A NATIONWIDE FRAMEWORK FOR SURVEILLANCE OF CARDIOVASCULAR AND CHRONIC LUNG DISEASES

Committee on a National Surveillance System for Cardiovascular and Select Chronic Diseases

Board on Population Health and Public Health Practice

INSTITUTE OF MEDICINE
OF THE NATIONAL ACADEMIES

THE NATIONAL ACADEMIES PRESS
Washington, D.C.
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This study was supported by contracts between the National Academy of Sciences and the Department of Health and Human Services (N01-OD-4-2139). Any opinions, findings, conclusions, or recommendations expressed in this publication are those of the author(s) and do not necessarily reflect the view of the organizations or agencies that provided support for this project.

International Standard Book Number-13: 978-0-309-21216-8
International Standard Book Number-10: 0-309-21216-2

Additional copies of this report are available from The National Academies Press, 500 Fifth Street, N.W., Lockbox 285, Washington, DC 20055; (800) 624-6242 or (202) 334-3313 (in the Washington metropolitan area); Internet, http://www.nap.edu.

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Suggested citation: IOM (Institute of Medicine). 2011. *A Nationwide Framework for Surveillance of Cardiovascular and Chronic Lung Diseases.* Washington, DC: The National Academies Press.

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Willing is not enough; we must do."
—Goethe

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This report has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise, in accordance with procedures approved by the National Research Council's Report Review Committee. The purpose of this independent review is to provide candid and critical comments that will assist the institution in making its published report as sound as possible and to ensure that the report meets institutional standards for objectivity, evidence, and responsiveness to the study charge. The review comments and draft manuscript remain confidential to protect the integrity of the process. We wish to thank the following individuals for their review of this report:

Robert Califf, Duke University Medical Center
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Although the reviewers listed above have provided many constructive comments and suggestions, they were not asked to endorse the final draft of the report before its release. The review of this report was overseen by **Patricia Buffler,** University of California, Berkeley. Appointed by the Institute of Medicine, she was responsible for making certain that an independent examination of this report was carried out in accordance with institutional procedures and that all review comments were carefully considered. Responsibility for the final content of this report rests entirely with the authors and the institution.

Acknowledgments

This report was made possible by support of the sponsors of this study, the National Heart, Lung, and Blood Institute (NHLBI) of the National Institutes of Health and the Division for Heart Disease and Stroke Prevention of the Centers for Disease Control and Prevention (CDC). The committee wishes to express special appreciation to Jean Olson of NHLBI and Robert Merritt of CDC who unfailingly responded to numerous questions and requests for information.

The work of the committee was aided by the valuable testimony and advice of many knowledgeable and experienced individuals. These individuals are: **Manal J. Aboelata,** Prevention Institute; **Toni Alterman,** National Institute for Occupational Safety and Health; **R. Graham Barr,** Columbia University; **Diane Bild,** NHLBI; **Gerard Criner,** Temple University Hospital; **Alfredo Czerwinski,** J. Glynn & Company; **Helen Darling,** National Business Group on Health; **Majid Ezzati,** Harvard University; **Lark Galloway-Gilliam,** Community Health Councils; **David Goff,** Wake Forest University; **Lisa Harris,** National Association of Public Hospitals and Health Systems; **Anne Kelsey Lamb,** Public Health Institute; **Elizabeth Lancet,** American Lung Association; **Ali Mokdad,** University of Washington; **Thomas Reilly,** Centers for Medicare & Medicaid Services; **Steve Sidney,** Kaiser Permanente; **Tyler Smith,** Department of Defense; **Edward Sondik,** National Center for Health Statistics; **Paul Varosy,** University of Colorado; **Mark Veazie,** Indian Health Service; and **Janet Wright,** American College of Cardiology.

The committee also wishes to thank the individuals who graciously responded to requests for information about data collection systems. These individuals are: **Sonia Angell,** New York City Department of Health and Mental Hygiene; **Alice Arnold,** University of Washington; **Susie Baldwin,** Los Angeles County Department of Health; **Jennifer Cartland,** Children's Memorial Research Center; **Nathaniel Cobb,** Indian Health Service; **Peter Damiano,** University of Iowa; **Ann Elixhauser,** Agency for Healthcare Research and Quality; **Paul Garbe,** National Center for Environmental Health; **Linda Geiss,** CDC; **Suzanne Hallquist,** University of North Carolina; **Ken Huelskamp,** American College of Cardiology; **Susan Jack,** National Center for Health Statistics; **Laura Kann,** CDC; **Nora Keenan,** CDC; **Russell Luepker,** University of Minnesota; **Greg Pawlson,** National Committee for Quality Assurance; **Sharina Person,** University of Alabama; **Randel Plant,** COPD Foundation; **Veronique Roger,** Mayo Clinic College of Medicine; **Wayne Rosamond,** University of North Carolina; **Esta Shindler,** Framingham Heart Study; **Jane Sisk,** National Center for Health Statistics; and **Paula Yoon,** CDC.

While we have tried to list all the individuals who provided input, it is possible that we have overlooked someone and, if that is so, we apologize.

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Summary

Chronic diseases are common and costly, yet they are also among the most preventable health problems (CDC, 2008). Comprehensive and accurate disease surveillance systems are needed to implement successful efforts to reduce the burden of chronic diseases on the U.S. population. A number of sources of surveillance data—including population surveys, cohort studies, disease registries, administrative health data, and vital statistics—contribute important and critical information about chronic disease. But no organized surveillance system provides the information needed to analyze how chronic disease impacts various U.S. populations by race, ethnicity, and locale; to identify public health priorities; or to track the progress of preventive efforts.

The National Heart, Lung, and Blood Institute of the National Institutes of Health and the Division for Heart Disease and Stroke Prevention of the Centers for Disease Control and Prevention (CDC) asked the Institute of Medicine (IOM) to form a committee that would develop a framework for building a national chronic disease surveillance system. This system would focus primarily on cardiovascular and chronic lung disease and be able to provide data for analysis of race, ethnic, socioeconomic, and geographic region disparities in incidence and prevalence, functional health outcomes, measured risk factors, and clinical care delivery. Questions for the committee to consider included:

1. Given what seems to be an existing consensus within the clinical and public health communities that national surveillance should be a high priority, is there a need for a new surveillance system and infrastructure? How might different types of surveillance systems (e.g., standard and sentinel) be included in a national system?
2. Might existing surveillance data collection efforts and cohort studies be strengthened or integrated to provide necessary surveillance information?
3. How might surveillance efforts include associated conditions, such as chronic lung disease, that contribute to cardiovascular disease and outcomes?
4. How could surveillance data be used to enhance research to address health disparities?
5. Given that fundamentally different approaches to national surveillance could be implemented, what general comments might be made on the relative efficiencies of an entirely new infrastructure versus one built upon currently existing systems?
6. How might local communities participate in the collection and use of data?

7. How might various federal, state, and local agencies collaborate in surveillance of cardiovascular and pulmonary disease data collection, determination of research priorities, and development of public policy?
8. What degree of validation is needed for cardiovascular disease (CVD) and pulmonary events identified through records systems?
9. Are there new initiatives that might be exploited for new national chronic disease surveillance efforts, such as:
    a. The Public Health Information Network (http://www.cdc.gov/phin/index.html), including BioSense, a real-time disease detection and monitoring system designed primarily for infectious disease surveillance (http://www.cdc.gov/phin/ library/documents/pdf/111759_biosense2.pdf);
    b. The National Electronic Disease Surveillance System project to establish a network of interoperable systems for "national integrated surveillance" (http://www.cdc.gov/phin/library/documents/pdf/111759_NEDSS.pdf);
    c. The Food and Drug Administration's (FDA's) Sentinel System;
    d. Local community surveys; or
    e. Efforts to increase use of electronic medical records (EMRs) nationally?
10. Can any existing data sources, such as Veterans Administration systems, health maintenance organization networks, or the Department of Defense systems, be used?
11. What can be learned from chronic disease surveillance in other developed countries?

The committee interpreted its charge as entailing a fairly broad approach with a focus on developing the overarching framework and the infrastructure required to create such a framework. While the committee determined it could identify kinds of data necessary for a framework (e.g., behavioral risk factors), identifying the specific data elements and the ways in which those elements are to be measured, collected, and verified is at a much more detailed level of specificity and requires greater resources than those available to the committee.

In considering the extent to which the framework should focus on chronic diseases in general, the committee concluded that the focus, as stated in the charge, should be "primarily on cardiovascular and chronic lung disease." An enlarged focus on chronic diseases would require an expanded committee, a lengthier study process, and additional resources that were not available. However, the committee resolved to devise a framework and infrastructure that could, to the extent possible, be applicable to other chronic diseases. The committee also recognized the rich history and accomplishments of existing surveillance resources, which can be leveraged in designing a national surveillance framework that would be timely, reliable, and comprehensive for current users of surveillance information.

EXISTING SURVEILLANCE EFFORTS

In health, surveillance systems are constructed to routinely provide information on the scope, magnitude, and cost of a health problem in order to regularly influence priority setting, program development, and evaluation of services or policies. While surveillance has been historically concentrated on notifiable[1] conditions or diseases, more recent surveillance efforts have expanded to track chronic diseases (Goodman et al., 2006). But surveillance of these conditions is difficult because of the challenges of disease definition, ascertainment, and differences in access to care, changes in clinical practice, multiple care providers, and lack of perceived threat of disease transmission. Surveillance of chronic conditions is also complicated by the need to provide data from several distinct domains (e.g., environment, income, education, race, ethnicity, and genetics) whose interaction leads to disparities in health and health care. A uniform framework for a nationwide surveillance system for these chronic conditions

[1] A notifiable disease is "a disease that, by statutory requirements, must be reported to the public health authority in the pertinent jurisdiction when the diagnosis is made. A disease deemed of sufficient importance to the public health to require that its occurrence be reported to health authorities" (Last, 2001). The Council of State and Territorial Health Epidemiologists works with the CDC to regularly update the list of notifiable diseases.

must also address the challenges that arise from the long-term nature of the risk and conditions, the large number of stakeholders involved in prevention and control, and the many potential objectives to be met.

A number of surveys, registries, cohort studies, administrative data, and vital statistics are used by different stakeholders to gather different kinds of information about these diseases. (See Appendix A for details.) Routine surveys are particularly valuable for obtaining information about prevalence and distribution of chronic diseases as well as about associated risk factors that may contribute to the diseases and their consequences. Major strengths of surveys include the breadth of information they offer and their ability to achieve representation through careful sampling. Such information may be helpful in tracking distributions, changes in rates, and comparisons among subgroups. In-person surveys, although costly, are widely considered to be most inclusive of the population because they select people based on where they are rather than whether they answer their telephone or respond to mail surveys, and because they often have high response rates. A limitation of many surveys is that they rely exclusively on respondent self-reporting to questionnaire items. Surveys are perhaps most valid for measuring many health behaviors, mental health conditions, perceived barriers to accessing health services, and reporting of symptoms.

A registry is one of the most powerful tools employed to record chronic diseases. Disease-specific registries are useful for capturing patient-specific data for individuals with selected conditions. Registries have significant advantages; the most important is that needed data are collected prospectively in the exact format required. Registries allow calculation of incidence rates and, if the cases are followed up regularly, a registry can also provide information on remission, exacerbation, prevalence, and survival. Despite the advantages of using registries for surveillance, they have some inherent limitations. Registries miss patients who visit healthcare providers not participating in the registry as well as individuals who do not receive care. Registries can also suffer bias due to unmeasured confounders and misclassification of patients into a registry. Furthermore, because of the time and effort required to enter data into a registry, clinicians may be reluctant to register patients or collect and record data on busy days, and busier clinicians may be less inclined to participate in registries altogether.

Another approach to surveillance is the cohort study. A cohort study is an epidemiological study which observes a group of individuals over time. The cohort design can be either prospective or retrospective. Retrospective cohort studies are less costly, shorter in duration, and useful for examining prior exposures; however, the resulting information is less complete and accurate than with the prospective approach. In general, the prospective cohort design offers several advantages, including the ability to provide incidence rates, determine a temporal sequence of events (exposure precedes disease), and examine multiple outcomes from the same exposure simultaneously. Additional advantages of the cohort design are the emphasis on systematic data collection and uniformly conducted measurements; however, a major weakness is the potential for differences between study volunteers and the general population. Other disadvantages include subject attrition, inability to produce prevalence data, and relative expense.

Claims data and medical record data obtained from manual chart abstraction or emerging electronic health records (EHRs) are two other sources of information that can be used for surveillance. Claims data can be used to enumerate each person's encounter or service. They can be collected for hospitalizations, outpatient visits, public program coverage, or private health insurance. Claims data may include sufficiently detailed information to analyze the incidence rate of a chronic condition, the social characteristics of people who receive services for the condition, and the types of services they receive. Claims data may also include geographic identifiers for persons or service providers and may be used to map geographic patterns of the incidence of hospitalizations, other services provided, and healthcare costs, which can be used in analyses of healthcare disparities. Although administrative claims data are useful at the macro level to describe patterns of use and mortality, limitations do exist, including coding errors, limited clinical information, and diagnostic misclassification such as underdiagnosis, overdiagnosis, and misdiagnosis common with cardiovascular and chronic lung diseases.

Data abstracted from medical records and EHRs can provide a detailed record of the history of health services for persons with chronic conditions and can be used to assess quality of care provided to persons with chronic conditions. If they include characteristics of the individual patients, the data also can be used to assess disparities in care. These data can be abstracted for use in registries and for combination into other data sets such as the Healthcare Cost and Utilization Project. However, like registry data, health services data exclude information extraneous to the healthcare delivery system.

Death records are an important source of information on mortality trends and patterns. Death certificate data, which include underlying and contributing causes of death, are compiled at the local and state levels in nearly all states and then shared with the National Center for Health Statistics. However, death certificates have been found to have relatively low sensitivity and specificity compared with medical chart review or autopsy findings. Coronary heart disease, for example, is overreported as a cause of death (Agarwal et al., 2010; Coady et al., 2001; Lloyd-Jones et al., 1998; Sington and Cottrell, 2002), and chronic obstructive pulmonary disease (COPD) is underreported (Camilli et al., 1991; Mitchell et al., 1971).

Currently, these surveys (some standardized and many non-standardized), registries, cohort studies, health services data, and mortality vital statistics provide an incomplete patchwork of information used by different stakeholders, often with inconsistent findings (Goff et al., 2007; Yeh and Go, 2010).

EMERGING SOURCES OF SURVEILLANCE DATA

Emerging experience with use of health information technologies (HITs) by both patients and providers suggests that, in addition to current sources of surveillance information, there will be expanding and potentially more efficient approaches to generating data for surveillance. Of particular interest is the potential, via the EHR, to economically and completely capture care events and processes and efficiently organize them into robust population- and condition-based registries. The healthcare reform goal of universal coverage, along with broad promotion of HITs (especially the EHR), may markedly increase the value of the medical record for disease surveillance. When an electronic medical record is suitably designed, analyses can be performed without duplicative data generation and handling. EHR data can also be used to generate lists of potential patients for a registry and prospectively register patients or to identify potentially eligible patients during healthcare visits. Challenges to using EHRs for surveillance include (1) a relatively small number of hospitals and practices currently use EHRs; (2) data collected in EHRs may not include the data necessary for effective surveillance; (3) sicker patients are likely to be overrepresented in EHRs due to more visits and more data per visit; (4) inaccurate coding occurs; and (5) patients with significant barriers will likely be underrepresented in EHRs. Despite these difficulties, EHRs have an important role to play in CVD and COPD surveillance, and their growth requires their inclusion when planning for a national surveillance system.

In addition to provider-generated EHR data, the generation and sharing of personal health data by individuals themselves (a trend that has its root in the emergence of the Internet) is a growing health data phenomenon with potential implications for timely, robust, and relevant surveillance. Recording of data by patients in HIT systems is being facilitated by a range of online personal health records. These may be provided by health insurers, integrated delivery systems, commercial providers of health information tools and support, and freestanding personal health records. Timely access to personally relevant information has been a driving force for patients to form, join, and share experiences and data within a range of organizations independent from historically defined public health, healthcare delivery, and health research entities. A new tool that has the potential to modify the future of surveillance and population-based research is the development of registries that integrate social networking, such as those registries currently recruiting in Kentucky[2] and Illinois.[3] An advantage of registries linked to social networking capabilities is that it creates the potential to follow people easily as they move around the country and even abroad, but their voluntary and non-randomized participation makes generalizing the data obtained from them challenging. Registries linked to social networking sites also produce privacy issues.

LEVELS AND USES OF SURVEILLANCE

Information and knowledge needs vary by perspective, and resources are rarely available to support all needs. Furthermore, the types of information and level of detail required will vary among users of surveillance data. A nationwide surveillance system will, therefore, involve consideration of a range of user groups. Table S-1 provides

[2] See https://www.mc.uky.edu/kyhealthregistry/ (accessed August 2, 2011).

[3] See https://whr.northwestern.edu/ (accessed August 2, 2011).

TABLE S-1 Levels and Users of Decision Making

Place and Roles	Place	Type	Who	What	Implementation Levers	Linkage to 2010 Reforms
Macro	• Federal • National • Nationwide	• Business coalitions • Benefit associations • National employer	• Federal government organizations • Medical society	Priority setting for • Regulation • Research and development • Objectives/ targets (e.g., *Healthy People 2020*)	• Legislation • Funding institutions (e.g., National Institutes of Health) • Communications	PPACA[a] • Comparative effectiveness • ACOs[b] ARRA[c] HIT/ONC[d] • Meaningful use
Meso	• Region • State • County • City • Community	• Regional/state employer • Small business	• State board • Medical society • Multispecialty medical group • Hospital medical staff • Public health workers • Local advocates	• Strategies • Programs and initiatives • Business planning and development • Performance reporting	• Budgets • Institutions and departments • Communications incentives	ACOs HIT funding • Beacon sites • Meaningful use • HIE[e] Chronic care Prevention
Micro	• Neighborhood • ZIP+4 • Home	• Schools • "Mom and Pop"	• Medical practice • Clinician • Family • Individual	• Interventions • Care and action plans • Outcomes	• Guidelines • Programs and initiatives • Communications • Payment or coverage	Insurance reform • Access • Free prevention services • Payment reform • Pay for performance • ACOs; medical home

[a] PPACA = *Patient Protection and Affordable Care Act*.
[b] ACO stands for Accountable Care Organization. According to the Medicare Payment Advisory Commission, "The defining characteristic of ACOs is that a set of physicians and hospitals accept joint responsibility for the quality of care and the cost of care received by the ACO's panel of patients" (MedPac, 2009).
[c] ARRA = *American Recovery and Reinvestment Act of 2009.*
[d] HIT stands for health information technology. ONC is the Office of the National Coordinator for Health Information Technology.
[e] HIE stands for health information exchange.

examples of different users of surveillance information that can be found at the micro, meso, and macro levels of surveillance.

Surveillance design will require explicit trade-offs in what is included and which user needs are addressed because resources are constrained by time, funding, data accessibility, and acceptability of use. For example, cost constraints may result in sampling rather than assessment of an entire population or force a trade-off between detailed biological examinations versus self-reported information. To protect the confidentiality of individual patient data, sample-size thresholds may be required for reporting. Strategies for improving surveillance will need to balance a number of challenges, including the tension between cost and granularity, and the differing needs of the various user constituencies of data.

CONCLUSIONS AND RECOMMENDATIONS

The committee concluded that a coordinated surveillance system is needed to integrate and expand existing information across the multiple levels of decision making in order to generate actionable, timely knowledge for a range of stakeholders at the local, state or regional, and national levels. The committee further concluded that existing surveillance data collection efforts and cohort studies can and should be strengthened and integrated to provide the basis of the system. Successful implementation of a framework for nationwide surveillance of cardiovascular and chronic lung diseases requires a mechanism to coordinate, monitor, and support the multiple data collection systems that contribute to the surveillance system. Furthermore, the system must provide ways to ensure that the elements collected by the system can evolve along with new knowledge about emerging risk factors, advancing technologies, and new understanding of the basis for disease.

Given that the mission of the Department of Health and Human Services (HHS) is to protect the health of and provide essential health services to Americans,[4] that HHS is already responsible for the funding and conduct of numerous surveillance efforts, and that it is in a position to bring together stakeholders from both the public and private sectors as well as those from multiple geographic levels, the committee concluded that HHS is in the best position to lead the development and implementation of the recommended framework and system. Because the recommended framework is based upon existing data collection approaches, it is crucial that those organizations responsible for the conduct of those activities be involved in determining ways to use and integrate existing approaches. The committee believes strongly that federal agencies should collaborate with the many state and local public agencies and the national and state-level nongovernmental organizations that conduct components of the proposed system.

Recommendation 1

The committee recommends that the Secretary of HHS establish and provide adequate resources for a standing national working group to oversee and coordinate cardiovascular and chronic pulmonary disease surveillance activity. This working group should include representatives from HHS (CDC, NIH, AHRQ, CMS, IHS, ONCHIT, FDA), other relevant federal agencies (e.g., VA and DOD), and tribal, state, and local public health agencies, as well as nongovernmental organizations with relevant roles in surveillance.

In a coordinated surveillance system, data are needed that can provide information on incidence and prevalence of relevant conditions over time; behavioral, clinical, and environmental risk factors (e.g., smoking); primary prevention (i.e., elimination of exposures that cause these diseases); secondary prevention efforts (i.e., early detection and intervention); tertiary prevention (i.e., management of symptomatic disease); health outcomes; costs; and, importantly, disparities in these factors by race or ethnicity, geographic region, and socioeconomic status.

Recommendation 2

The committee recommends that HHS place priorities for surveillance on systems that can overtly

- **Track progress on nationally recognized goals and indicators regarding cardiovascular disease and chronic pulmonary disease incidence, prevalence, and prevention (e.g., Healthy People);**
- **Evaluate and inform national, state, and local efforts to control, reduce, and prevent these chronic diseases;**
- **Enable effective public health actions and policies;**
- **Improve treatment outcomes;**
- **Monitor and enhance quality of life; and**
- **Reduce disparities in risk and burden of these diseases.**

[4] See http://govinfo.library.unt.edu/npr/library/status/mission/mhhs.htm (accessed August 2, 2011).

Many chronic cardiovascular and lung conditions have common risk factors and follow a broadly similar natural history within patients and populations, which enabled the committee to adapt for its purposes a conceptual framework developed by Wingo and colleagues (2005) for cancer surveillance. In this framework (Figure S-1), the trajectory of chronic disease is integrated with the logic and practices of primary, secondary, and tertiary prevention to provide the core of the framework. The framework organizes data from traditional, evolving, and novel surveillance sources to reflect the development and progression of chronic conditions over a life course. It is critical to collect data on these risk factors in order to identify precursors prior to or at the very earliest states of disease. The design also captures the impact of prevention as both a goal and an interventional intent. Information emerging from this core can be assembled into both cross-cutting and stage-specific metrics to inform the actions of decision makers in multiple roles and at the macro, meso, and micro levels of the health and healthcare systems. This general framework, while evolved specifically for chronic heart and lung diseases, is anticipated to be broadly applicable to other chronic health conditions, including the increasingly common co-occurrence of multiple chronic health conditions in the same individual.

Recommendation 3

The committee recommends that HHS adopt the framework illustrated in Figure S-1 as a guide for national surveillance of cardiovascular and chronic lung diseases.

Impressive gains have been achieved in life expectancy for the overall American population, as well as distinct subpopulations defined by race and ethnicity. However, inequities in health status and health systems remain in many neighborhoods, cities, states, and regions. The committee explored the need for data that would facilitate understanding of the effects of race and ethnicity on health and health outcomes and concluded that it would endorse the recommendations of the IOM report *Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement* (2009). That report recommends that organizations collecting data related to health and heath

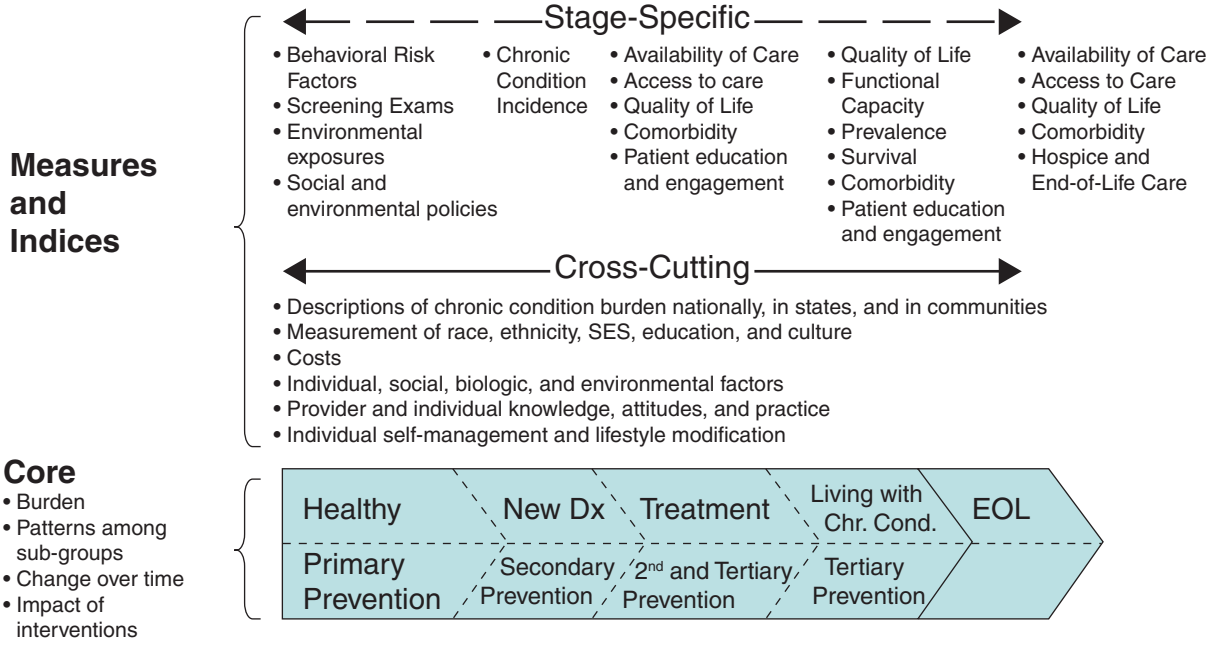

FIGURE S-1 Framework for a national surveillance system for cardiovascular and chronic lung diseases.
SOURCE: Adapted from Wingo et al. (2005).

care should not only use the OMB race and Hispanic ethnicity categories but also select other ethnicity categories to include from a national standard set.

An effective national surveillance system will require more effective and efficient linkages of conventional surveillance data to contextually relevant information, such as socioeconomic status, birthplace, acculturation, geography, language, and health insurance. Also, to the extent possible, there should be standard definitions of key risk factors, outcomes, and interventions as well as a mechanism to link subjects and providers across the different data sources. The committee believes that serious consideration should be given to the scientific and cost considerations as well as the ethical and privacy issues associated with the use of a unique personal health identifier and the use of standardized case definitions and data collection elements so that results can be compared within and across different geographical areas. Furthermore, the integrated system should be able to evolve to allow for recognition of new disease entities, for understanding how changes in public policy affect the disease being studied, and for determining how risk factors can have a major impact on incidence and prevalence of other diseases. Functional capacity, quality of life, and patient engagement and action measures are needed. Enhancing the use of current data sources requires coordination of data collection efforts, harmonization of some elements, expansion to include patient outcomes, and community-tailored items. Coordination of data collection efforts across federal, state, and local systems and healthcare delivery organizations requires, to the extent possible, standard definitions of key risk factors and outcomes, interventions, and a mechanism to link subjects and providers across the different data sources.

Recommendation 4

The committee recommends that the group that oversees and coordinates surveillance activity be charged with:

- **Selecting surveillance indicators and, periodically, undertaking a review of the surveillance system in order to identify and incorporate necessary modifications;**
- **Improving collaboration and coordination among federal, tribal, state, and local agencies and nongovernmental organizations around the collection, compilation, and dissemination of surveillance information;**
- **Collecting and making available all types of surveillance data (survey, registry, EHR) at the most granular level consistent with protection of data privacy and confidentiality and, when feasible, linked with other data sources (i.e., clinical databases, public health data);**
- **Formation of public–private partnerships with the nongovernmental health sector; and**
- **Development of data sets for surveillance sources that can be made broadly accessible to a variety of users to support and guide action to improve health at the national, state, and local levels.**

While the working group functions are as outlined above, a mechanism is needed to facilitate implementation of the enhanced and integrated system as it evolves. To further an understanding of the basis and trajectories of cardiovascular and chronic lung diseases, the information collected by the system must be available and accessible to a variety of stakeholders. While data from national surveys conducted by the federal, state, or local governments are usually readily available, private sources of data are frequently inaccessible or accessible only with great difficulty. A greater national investment is needed to ensure that chronic disease surveillance data are accessible to potential data users with a wide range of technical capacities.

Recommendation 5

The committee recommends that the Secretary of HHS designate a federal office with the following responsibilities:

- **Producing and disseminating regular surveillance reports and key indicators of progress that support and stimulate action aimed at improving health and reducing disparities at the national, state, and local levels;**

- **Assuring that the surveillance data are accessible to a broad spectrum of users (e.g., public health agencies, health systems, researchers, policy makers, and advocacy groups) at all levels while protecting privacy and documenting the extent of that use; and**
- **Implementing the recommendations of the national working group.**

As discussed earlier, the life course perspective is important to understanding the trajectory of chronic diseases. Also needed are comparable data that enable analysis across different subpopulation groups and geographic levels and that can be linked across data sources. The committee concluded that existing data collection mechanisms provide valuable information that, with enhancements, can serve to meet the surveillance needs for CVD and chronic lung disease.

Recommendation 6

The committee recommends that HHS coordinate with voluntary bodies operating disease registries to promote collection and harmonization of data.

Recommendation 7

The committee recommends that governmental and nongovernmental organizations enhance existing national data sources in the following manner:

- **Information on all elements of the recommended framework should be collected on the U.S. population across the life span, with special attention paid to collecting information on diverse and changing populations, including information on disparities.**
- **A minimum subset of actionable indicators as identified by the working group should be collected using comparable measures at the national, state, and local levels.**
- **Data should be increasingly linked across health domains and data sources.**

Effective interventions to prevent CVD and chronic lung disease, many of which take place at the local level, require tracking information at multiple geographic levels—local and state as well as national. Community-tailored survey items will be necessary to understand the extent to which conditions vary by characteristics such as socioeconomic status, race/ethnicity, or geographic setting (e.g., urban versus rural). To foster efforts to reduce these disparities, a surveillance system must be capable of providing data for analysis of disparities not only at the national level but also at the regional, state, and local levels. Furthermore, the system will be most beneficial if comparisons can be made between and among various communities; this requires collection of comparable data.

Recommendation 8

The committee recommends that HHS develop a cardiovascular and chronic pulmonary disease survey question bank and technical support for use by tribal, state, and local agencies; nongovernmental organizations; and individual researchers for the purpose of enhancing the quality and comparability of population health surveys in order to identify trends in risk factors, diseases, treatments, and outcomes.

There is great potential for the use of electronic health records (EHRs) as sources of surveillance information. Currently, those records focus primarily on recording clinical information (e.g., diagnoses, laboratory work, and treatments). However, behavioral, social, and physical environmental risk factors in the development of cardiovascular and chronic lung diseases are key to understanding the development of these diseases. The Office of the National Coordinator for Health Information Technology (ONCHIT) is responsible for identifying the minimum data to be collected for EHRs. ONCHIT is in a position to take action that would significantly enhance the surveillance information contained in EHRs.

Recommendation 9

The committee recommends that the Office of the National Coordinator for Health Information Technology expand the minimum data for electronic health records to include behavioral, social, and environmental risk factors for cardiovascular and chronic lung diseases in validated, interoperable ways in order to enhance the quality of surveillance data for these conditions.

Because EHRs are currently in use in only a minority of hospitals and practices, several interim steps are needed before their potential can be realized. Expansion of EHRs to the majority of clinical care settings will require significant investment in purchasing necessary equipment and software as well as staff training. Additional resources will need to be devoted to major issues such as interoperability of EHR systems and harmonization of data standards.

Many existing sources of surveillance information provide high-quality data that are critical to understanding the trajectory of cardiovascular and chronic lung diseases. However, those data lack standardization and cannot be linked across sources, and many of them are not readily accessible. Furthermore, there is a need for collection of data that can be analyzed by demographic variables such as race/ethnicity, socioeconomic status, and geography. The committee believes the recommendations provided in this report lay the foundation or framework and the basics of the infrastructure needed for integrating and enhancing current CVD and COPD surveillance activities so that they can evolve into the complex, interdependent system needed.

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Introduction

Chronic diseases such as cardiovascular disease (CVD), respiratory illness, and cancer are the leading causes of death and disability in the United States. They caused more than 1,440,000 deaths in 2007 (CDC, 2009) and significantly affected the health of millions of others (AHA, 2009). Although death rates from heart disease declined from 1995 to 2005 (Lloyd-Jones et al., 2010), heart diseases are still responsible for more than one in every four deaths in the United States (Heron et al., 2009). Furthermore, estimated direct costs (e.g., healthcare services and medications) and non-direct costs (e.g., lost productivity) due to heart disease were more than $286 billion in 2010 (Roger et al., 2010).

Although heart disease is the leading cause of death in the United States, population groups are not equally affected. For example, 41.4 percent of blacks have hypertension compared to 28.1 percent of whites (Roger et al., 2010). Heart disease prevalence and death rates also vary by geographic region. The highest death rates from heart disease are found in Appalachia, the southeastern coastal plains, the southern regions of Georgia and Alabama, the lower Mississippi River Valley, and most of Oklahoma (CDC, 2007). A similar geographic pattern is observed for cerebrovascular disease and stroke (Roger et al., 2010).

Chronic lower respiratory diseases, including chronic obstructive pulmonary disease (COPD), are now the third leading cause of death in the United States (after heart disease and malignant neoplasms). COPD, which includes chronic bronchitis and emphysema, was responsible for 137,082 deaths in 2009 (Kochanek et al., 2011), and COPD may affect as many as 24 million people in the United States (CDC, 2010).

Unlike heart disease, which has had a consistent decrease in death rates over the past several decades, the overall death rate from COPD among whites increased by 67 percent from 1980 to 2000 while among blacks the death rate increased by 87 percent (Mannino et al., 2002). The mortality from COPD in 2006 was lowest for African American women (18.9 per 100,000), followed by African American men (37.7 per 100,000), Caucasian women (39.1 per 100,000), and Caucasian men who had the highest mortality rate (50.5 per 100,000) (ALA, 2010). Data are limited on COPD prevalence and death rates among Hispanics or Latinos and among Asian and Pacific Islanders.

The costs of lung diseases were projected to be $177 billion in 2009, of which $114 billion was attributed to direct health expenditures, with the remaining $64 billion due to indirect costs of morbidity and mortality (NHLBI, 2010). The direct costs of COPD in 2005 dollars were estimated at about $21.8 billion, and the indirect costs (e.g., loss of work time and productivity and premature mortality) contributed an additional $10 billion (Foster et al., 2006).

While common and costly, most chronic diseases are substantially preventable and amenable to improved management for better health outcomes. Behavioral risk factors and clinical precursors for cardiovascular disease and chronic lung disease are well characterized. The major modifiable risk factors for CVD are a diet high in saturated fat and sodium, smoking, high blood cholesterol, high blood pressure, physical inactivity, obesity and overweight, and diabetes mellitus (AHA, 2009; Roger et al., 2010). For COPD, the single most important risk factor is smoking (Ezzati and Lopez, 2003); other risk factors include occupational exposures, environmental tobacco smoke, other indoor air pollutants, outdoor air pollutants, respiratory tract infections, asthma, physical inactivity, poor nutrition, low socioeconomic or educational status, and genetic susceptibility (Eisner et al., 2010; Salvi and Barnes, 2009; Svanes et al., 2010). While a number of sources of data exist, there is no systematic, integrated, and timely tracking and reporting of these behaviors and conditions across different geographic settings or population subgroups in the United States. Additionally, the monitoring of acute clinical events and chronic disease management is fragmented and incomplete. These gaps have detracted from our ability to target focused and effective local and national action to improve health.

SURVEILLANCE

Surveillance systems are constructed to routinely inform public health and clinical practitioners, as well as policy makers, other stakeholders, and the general public, of the scope, magnitude, and cost of a health problem in order to regularly influence priority setting, program development, and evaluation of services or policies. The ultimate goal of these monitoring systems is to use information gleaned from surveillance data to take action to reduce morbidity and mortality and improve health, within a framework of finite resources used in an efficient and cost-effective way. Periodic evaluation of the effectiveness and efficiency of surveillance systems in disseminating useful information and impacting decision making is recognized as being intrinsically important (CDC, 2001).

Historically, surveillance systems concentrated on notifiable[1] conditions or diseases, for which states required healthcare providers and laboratories to report diseases and conditions of public health interest to a local or state authority (Goodman et al., 2006). Although the quality, cost, and utility of these systems have varied, clear mechanisms for reporting notifiable conditions are typically established in statute, responsibilities are delineated, and the number of involved stakeholders is somewhat circumscribed. In addition, notifiable conditions tend to have characteristics that facilitate easier reporting, such as reliable and specific laboratory tests, discernible communicable threats to public health, and immediately actionable public health interventions. Perhaps most importantly, the objectives of these surveillance systems typically have been quite focused, based on counting cases rather than on estimating rates, and often centered on control of further disease transmission.

In the past 30 years, surveillance systems have expanded in scope and mechanism to also track non-notifiable conditions, particularly cancer registries for surveillance of malignant neoplasms. These surveillance systems have also expanded to include common, multifactorial diseases such as cardiovascular and chronic lung diseases. The tracking of disease events for these diseases is more difficult because of the challenges of disease definition, ascertainment, and differences in access to care, changes in clinical practice, multiple care providers, and lack of perceived threat of disease transmission. Tracking of health events themselves is insufficient because prevention of diseases with complex, multiple contributing factors requires regular collection of surveillance data on the diseases and their multifaceted causes. Prevention efforts require systematically collected information on trends and population distributions of a range of modifiable health behaviors, clinical preventive service use, and disease precursors themselves. Precise information on the denominator population from which the cases occur is also needed, but it is often challenging to obtain. Due to the chronic and debilitating nature of disease, as well as costs of care, indicators tracking the short- and more long-term outcomes of chronic disease management are also critically important.

[1] A notifiable disease is "a disease that, by statutory requirements, must be reported to the public health authority in the pertinent jurisdiction when the diagnosis is made. A disease deemed of sufficient importance to the public health to require that its occurrence be reported to health authorities" (Last, 2001). The Council of State and Territorial Health Epidemiologists works with the CDC to regularly update the list of notifiable diseases.

Current surveillance efforts for cardiovascular and chronic lung diseases include surveys (e.g., the Behavioral Risk Factor Surveillance System, or BRFSS, and the National Health and Nutrition Examination Survey, or NHANES); registries (e.g., Cardiac Arrest Registry to Enhance Survival, the National Cardiovascular Data Registry, and the COPD Foundation Research Registry); cohort studies (e.g., the Framingham Heart Study); health services data such as claims data; and vital statistics. However, no integrated national surveillance system currently exists for these conditions. Instead, these surveys (some standardized and many non-standardized), registries, cohort studies, and mortality vital statistics provide an incomplete patchwork of information that is used by different stakeholders, often with inconsistent findings (Goff et al., 2007; Yeh and Go, 2010).

The challenges of building on existing surveillance efforts or developing a new relatively simplified, uniform framework for a national surveillance system for these chronic conditions arise from the long-term nature of the risk and conditions, together with the large number of stakeholders involved in prevention and control and the many potential objectives to be met. Although mandatory, notifiable events may have their own set of challenges—such as incomplete ascertainment and difficulty in establishing denominators—and the lack of such CVD or chronic lung disease events other than death has led many jurisdictions and institutions to develop their own tracking systems to meet their immediate objectives. They have also tried to harness administrative data sets for disease monitoring or to rely on sample surveys of varying geographic and demographic coverage. Finally, the lifelong nature of CVD and chronic lung disease development and the lack of effective treatments to fully prevent or cure these conditions require a conceptual framework that incorporates a life-course approach.

CONTEXT

In recent years, leading professional societies, researchers, and government organizations have called for improved tracking systems and expanded surveillance for chronic diseases to guide improvements in prevention and treatment (Brownson and Bright, 2004; CDC, 2008; Frieden, 2004; Goff et al., 2007; Nichol et al., 2008; Spertus et al., 2005). The following section provides a summary of the recommendations of several organizations for improving the surveillance of cardiovascular disease.

Cardiovascular Disease

In 2007, the American Heart Association (AHA) published its *Essential Features of a Surveillance System to Support the Prevention and Management of Heart Disease and Stroke,*[2] which offered an overview of existing surveillance efforts for cardiovascular disease and made recommendations for addressing identified gaps (Goff et al., 2007). The report emphasized the need for enhanced health tracking systems to measure progress toward the AHA strategic goals of a 25 percent reduction in heart disease, stroke, and associated risk factors and the national heart disease and stroke prevention goals put forth in *Healthy People 2010*. The recommendations were intended to guide the development of a comprehensive surveillance system to support these goals and reduce the burden of heart disease and stroke. The authors of the report noted that there are numerous barriers to establishing a new and comprehensive surveillance system, particularly methodological challenges, privacy concerns, and cost. They also emphasized the importance of surveillance data at the national, state, and local levels to support federal efforts in the prevention and management of heart disease and stroke.

The AHA recommendations called for creation of a national heart disease and stroke surveillance unit (similar to the Centers for Disease Control and Prevention's [CDC's] National Diabetes Surveillance System) to produce annual reports on key indicators of prevention and management of heart disease and stroke. In addition, it was recommended that CVD be classified as a reportable condition, that data elements be standardized across surveys, that oversampling be done to provide meaningful estimates on ethnic subgroups, that healthcare data systems and electronic health records be linked, and that studies be conducted to establish the validity of self-report and provider report measures in national databases.

[2] See http://circ.ahajournals.org/cgi/content/full/115/1/127 (accessed August 2, 2011).

The report also recommended that national surveys should include additional measures of such risk factors as information on awareness, detection, treatment, and control of physical inactivity, unhealthy dietary practices, cigarette smoking, and obesity, and that indicators, systems, and methods be developed, tested, and implemented for the following:

- Collection of data on patients with newly diagnosed disease in the outpatient setting; and
- Surveillance of policies and environmental conditions related to
  - — Physical inactivity and unhealthy diet; and
  - — Symptom knowledge and recognition, acute healthcare-seeking behavior, availability of automated external defibrillators, and capabilities of the pre-hospital care system.

Another report, *A Population-Based Policy and Systems Change Approach to Prevent and Control Hypertension* by the Institute of Medicine Committee on Public Health Priorities to Reduce and Control Hypertension in the U.S. Population (IOM, 2010a), highlighted the importance of data-collection efforts in addressing any public health problem. Specifically noted was the need for reliable data to determine the burden of hypertension, characterize patterns among subgroups of the population, assess changes in the problem over time, and evaluate the success of interventions noted. According to this report, government surveys, such as NHANES, provide the best data to examine secular trends in hypertension, but there is uncertainty about the validity of long-term temporal data reported in these surveys. The committee found that efforts to strengthen hypertension surveillance and monitoring were critically needed. The report also called for improved analysis and reporting of understudied populations, for example, children, racial and ethnic minorities, the elderly, and various socioeconomic groups.

The report emphasized the importance of hypertension data for states and local health jurisdictions and noted that NHANES is not designed to provide estimates of hypertension awareness, treatment, and control at these levels. Expanding the use of local-level HANES (e.g., those conducted in New York City and in Wisconsin) or drawing on other reliable and available population-based data sets to monitor local hypertension trends was suggested. The committee also recommended collection of accurate information about sodium intake and the content of sodium in specific foods.

The IOM Committee on Preventing the Global Epidemic of Cardiovascular Disease: Meeting the Challenges in Developing Countries highlighted the importance of local data in its report *Promoting Cardiovascular Health in the Developing World* (IOM, 2010b). The committee noted that governments must determine the extent and nature of cardiovascular risk in their local populations and assess their needs and capacities to address cardiovascular and related chronic diseases. The report emphasized that local data are necessary to compel action, inform local priorities, and measure the impacts of policies and programs. In addition to local data, the committee also found that a consistent reporting mechanism at the global level was needed to track progress, stimulate ongoing dialogue, and galvanize stakeholders. This publication suggested building on continuing efforts of the World Health Organization to report on the global status of non-communicable diseases, and included regional, subnational, and national actions and global coordination as means of promoting cardiovascular health.

Another approach to improving chronic disease surveillance has been proposed to the National Heart, Lung, and Blood Institute (NHLBI) based on information obtained in a study by Murray and colleagues (2006). The suggested approach would survey eight racial/ethnic groups identified in the 2006 study and would link data from surveys to health service records, registries, and the national death index. The approach is intended to provide a greater understanding of risk factors associated with racial and ethnic disparities and give a small number of diverse localities data that can be used to develop appropriate interventions. Murray and colleagues also emphasized the limitations of current data-collection approaches such as NHANES, which provides data that are nationally representative but with insufficient samples for state and local estimates, and BRFSS, which relies on self-reported data. Neither survey is integrated with administrative data such as hospital discharges or provider registries to estimate longitudinal effects of risk factor exposures.

Lung Disease Surveillance

While the committee found no published articles containing recommendations for improving the surveillance of chronic obstructive pulmonary disease, Elizabeth Lancet, vice president for research at the American Lung Association, met with the committee in open session and offered suggestions for improving surveillance. These suggestions included:

- Improving and expanding the collection of demographic information, such as race/ethnicity, country of origin, nativity status, socioeconomic factors, and sexual orientation and gender;
- Standardization of measures, including definitions of conditions, risk factors, and use of ICD codes;
- Collection of information at various geographic levels, including national, state, county, city, ZIP code, and Census tract; and
- Collection of comorbidities or disease interaction, such as air quality and respiratory disease or COPD and lung cancer.

STUDY CHARGE

NHLBI and the CDC Division for Heart Disease and Stroke Prevention asked the Institute of Medicine to form a committee that would develop a framework for building a national chronic disease surveillance system focused primarily on cardiovascular and chronic lung disease that is capable of providing data for analysis of race, ethnic, socioeconomic, and geographic region disparities in incidence and prevalence, functional health outcomes, measured risk factors, and clinical care delivery. Questions for the committee to consider included:

1. Given what seems to be an existing consensus within the clinical and public health communities that national surveillance should be a high priority, is there a need for a new surveillance system and infrastructure? How might different types of surveillance systems (e.g., standard and sentinel) be included in a national system?
2. Might existing surveillance data collection efforts and cohort studies be strengthened or integrated to provide necessary surveillance information?
3. How might surveillance efforts include associated conditions, such as chronic lung disease, that contribute to cardiovascular disease and outcomes?
4. How could surveillance data be used to enhance research to address health disparities?
5. Given that fundamentally different approaches to national surveillance could be implemented, what general comments might be made on the relative efficiencies of an entirely new infrastructure versus one built upon currently existing systems?
6. How might local communities participate in the collection and use of data?
7. How might various federal, state, and local agencies collaborate in surveillance of cardiovascular and pulmonary disease data collection, determination of research priorities, and development of public policy?
8. What degree of validation is needed for cardiovascular disease (CVD) and pulmonary events identified through records systems?
9. Are there new initiatives that might be exploited for new national chronic disease surveillance efforts, such as:
    a. The Public Health Information Network (http://www.cdc.gov/phin/index.html), including BioSense, a real-time disease detection and monitoring system designed primarily for infectious disease surveillance (http://www.cdc.gov/phin/ library/documents/pdf/111759_biosense2.pdf);
    b. The National Electronic Disease Surveillance System (NEDSS) project to establish a network of interoperable systems for "national integrated surveillance" (http://www.cdc.gov/phin/library/documents/pdf/111759_NEDSS.pdf);
    c. The FDA's Sentinel System;
    d. Local community surveys; and
    e. Efforts to increase use of electronic medical records nationally.

10. Are there existing data sources, such as Veteran's Administration systems, health maintenance organization networks, or the Department of Defense systems that could be utilized?
11. What can be learned from chronic disease surveillance in other developed countries?

COMMITTEE APPROACH

Over the course of this 24-month study, the 16-member committee held six in-person meetings and conducted extensive literature reviews and Internet searches regarding cardiovascular disease and chronic lung disease incidence, prevalence, risk factors, prevention, treatments, health outcomes, and costs. Additionally, three public workshops were held to gather data on existing systems for surveillance of these conditions and their risk factors.

A major focus of early committee discussions revolved around exploring what was meant by the term "framework." The committee decided that its charge required a fairly broad approach with a focus on developing the overarching framework and the infrastructure required to create such a framework. While the committee determined it could identify kinds of data necessary for a framework (e.g., behavioral risk factors), identifying the specific data elements and the ways in which those elements are to be measured, collected, and verified is at a level of specificity and requires greater resources than those available to the committee.

Another area of discussion related to the extent to which the framework should focus on chronic diseases in general, or be oriented more specifically to cardiovascular and chronic lung diseases. The charge mentions both. The committee concluded that the focus, as stated in the charge, should be "primarily on cardiovascular and chronic lung disease." An enlarged focus on chronic diseases would require an expanded committee, a lengthier study process, and additional resources that were not available. However, the committee resolved to work to ensure that the framework and infrastructure it would recommend could, to the extent possible, be capable of evolution so that it could apply to other chronic diseases.

Throughout the course of its discussions, the committee recognized the importance of leveraging the rich history and accomplishments of existing surveillance resources and engaging in designing a national surveillance framework that would be timely, reliable, and comprehensive for current users of surveillance information. Also, by design, the framework would be durable and relevant over time to accommodate evolving data resources, decisions, and decision makers. The committee recognized early on that in the case of chronic health conditions such as heart and lung diseases, overall population health management, preventive interventions, and delivery of healthcare services are increasingly intermingled. Furthermore, with growing use of health information technologies, health-related data that can inform surveillance-related decisions are becoming more diverse in type and definition and more abundant. The committee performed an in-depth assessment of the growing heterogeneity of data that could be useful for surveillance plus the strengths and challenges offered by all potential data sources. Of particular interest to the committee, as well as a particular challenge to address and anticipate fully, are the opportunities for capturing and integrating the experience of patients and actions of care providers within the increasingly dynamic health system into the surveillance framework.

REPORT CONTENTS

This chapter has provided a brief introduction of the prevalence and costs of cardiovascular and chronic lung disease, an overview of the status of surveillance for these conditions, a discussion of existing recommendations for improving that surveillance, and a brief overview of the committee process. Chapter 2 (Cardiovascular Disease) and Chapter 3 (Chronic Lung Disease) provide discussions of prevalence, mortality, costs, risk factors, prevention, and treatment for these diseases. Chapter 4 discusses health disparities in cardiovascular and chronic lung diseases in terms of age and gender; race and ethnicity; nativity and immigration; geography, residence, and environment; and socioeconomic factors. Chapter 5 explores existing surveillance data collection efforts, including surveys, registries, cohort studies, administrative and claims data, data regarding hospital performance, and international chronic disease surveillance efforts, concluding with a discussion of the strengths and limitations of these efforts. Chapter 6 discusses the various stakeholders and their differing needs for surveillance data as well as emerging opportunities for surveillance data collection. Chapter 7 presents the committee's recommendations.

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2

Cardiovascular Disease

EPIDEMIOLOGY

Epidemiological data on heart disease, stroke, and associated risk factors are compiled and published annually in the *Heart Disease and Stroke Statistical Update*. This publication is a collaborative effort of the American Heart Association (AHA), the Centers for Disease Control and Prevention, the National Institutes of Health, and other government agencies. This chapter draws from the most recent edition of the report, the *Heart Disease and Stroke Statistics 2011 Update*, in addition to other resources to provide an overview of the burden of cardiovascular diseases in the United States.

The AHA reports that approximately 82.6 million people in the United States currently have one or more forms of cardiovascular disease (CVD), making it a leading cause of death for both men and women (Roger et al., 2010). Common types of cardiovascular disease include coronary heart disease (CHD), stroke, hypertension, and congestive heart failure. Other forms of CVD are atrial and ventricular arrhythmias, congenital cardiovascular disorders, rheumatic heart disease, peripheral artery disease, and other conditions affecting the circulatory system, such as deep vein thrombosis and pulmonary embolism.

Prevalence and Incidence of Cardiovascular Disease

Coronary Heart Disease

An estimated 16.3 million Americans aged 20 and older have CHD, a prevalence of 7 percent. The prevalence for men is 8.3 percent and for women is 6.1 percent. Non-Hispanic white men have the highest prevalence of CHD at 8.5 percent, followed by non-Hispanic black men at 7.9 percent and Mexican American men at 6.3 percent. For women, non-Hispanic black women have the highest rate of CHD at 7.6 percent, followed by non-Hispanic white women at 5.8 percent and Mexican American women at 5.6 percent (Roger et al., 2010). Data from the Strong Heart Study, funded by the National Heart, Lung, and Blood Institute (NHLBI), found that the incidence of CHD in American Indians between the ages of 45 and 74 was 17.9 per 1,000 person-years: 23.2 per 1,000 person-years in men and 14.8 in women (Lee et al., 2006).

CHD includes heart attacks (myocardial infarction) and angina pectoris (chest pain). In the U.S. population, 7.9 million individuals have suffered heart attacks and 9 million have experienced angina pectoris. Data from Roger and colleagues (2010) show that the overall prevalence for myocardial infarction in American adults aged 20 and

older is 3.1 percent. Men are more likely than women to have had a heart attack. The prevalence among non-Hispanic white men and non-Hispanic black men is the same (4.3 percent), while Mexican American men are less likely to have had a heart attack (3 percent). Both non-Hispanic white women and non-Hispanic black women experience higher rates of heart attack (2.1 and 2.2 percent, respectively) than do Mexican American women at 1.1 percent. Data from the 2009 Behavioral Risk Factor Surveillance System (BRFSS) show the highest prevalence of heart attack is in West Virginia (6.5 percent) and Kentucky (5.9 percent). The lowest rate (1.9 percent) was reported in the District of Columbia. West Virginia also had the highest prevalence of angina or coronary heart disease, while the District of Columbia had the lowest (Roger et al., 2010).

Stroke

About 7 million Americans aged 20 or older have had a stroke. Each year approximately 610,000 experience their first stroke and another 185,000 experience a recurrence (AHA, 2009). Approximately 87 percent of all strokes are ischemic; 10 percent result from intracerebral hemorrhage and 3 percent result from subarachnoid hemorrhage.

Approximately 2.7 percent of men and 2.5 percent of women aged 18 or older have a history of stroke. According to the 2009 BRFSS, the states with the highest prevalence of stroke were Alabama and Oklahoma, and the lowest was Colorado (Roger et al., 2010). NHLBI reports that blacks have nearly twice the risk of first-time stroke when compared with whites. The age-adjusted stroke incidence rates at ages 45–84 are 6.6 per 1,000 persons in black males, 3.6 in white males, 4.9 in black females, and 2.3 in white females (NHLBI, 2006).

Data from the Strong Heart Study found that incidence of stroke was 6.8 per 1,000 persons (age- and sex-adjusted) in American Indians (Zhang et al., 2008). Data from the 2005 BRFSS also showed that the prevalence of stroke was higher among American Indians/Alaskan Natives and multiracial persons than among whites. Increased incidence of stroke has been reported among Mexican Americans when compared with non-Hispanic whites. Stroke symptoms are more commonly reported among individuals with fair to poor perceived health status and those with lower income and educational attainment: approximately twice the proportion of those with less than 12 years of education reported a history of stroke compared with college graduates (HHS, 2006).

Hypertension

Approximately 76.4 million—one in three—American adults have high blood pressure (hypertension), defined as an elevated pressure of 140 mmHg systolic or higher and/or 90 mmHg diastolic or higher, use of antihypertensive medication, or being told at least twice by a physician or other health professional that one has high blood pressure. National Health and Nutrition Examination Survey (NHANES) data collected between 2003 and 2006 reveal that among adults with hypertension, 78 percent were aware of their condition and 68 percent were using antihypertensive medication; however, less than 64 percent of those receiving treatment had their condition controlled (Roger et al., 2010).

The prevalence of hypertension increases with age. About half of individuals between the ages of 60 and 69, and three quarters of individuals over the age of 70, have hypertension. Framingham Heart Study investigators found the lifetime risk of hypertension to be approximately 90 percent for men and women who had normal blood pressure at age 55 or 65 and survived to ages 80–85. More men than women have hypertension before age 45, similar proportions of men and women experience hypertension between the ages of 55 and 64, and women are more likely to have hypertension later in life (NCHS, 2007). U.S. blacks have the highest prevalence of hypertension in the world. They develop the disease earlier in life, have much higher average blood pressures than whites do, and as a result have greater rates of nonfatal and fatal stroke, heart disease deaths, and end-stage kidney disease. The prevalence of hypertension increased among blacks and whites in the United States between 1999 and 2002, rising from 35.8 to 41.4 percent among blacks and from 24.3 to 28.1 percent among whites (Roger et al., 2010). Factors such as birth outside of the United States, speaking a language other than English at home, and fewer years spent living in this country are associated with lower rates of hypertension (Moran et al., 2007).

Heart Failure

Recent data show that approximately 5.7 million Americans have congestive heart failure. The majority of individuals with heart failure have antecedent hypertension, and those with a blood pressure of 160/90 mmHg or greater have twice the lifetime risk of heart failure compared with those whose blood pressure is less than 140/90 mmHg (Roger et al., 2010). Recent studies have reported improved survival from heart failure, although incidence has not declined in the past 20 years (Barker et al., 2006). Heart failure before age 50 is more prevalent among blacks than whites. Incidence rates (age-adjusted, per 1,000 person years) from the NHLBI-funded Atherosclerosis Risk In Community (ARIC) study were 3.4 for white women, 6 for white men, 8.1 for black women, and 9.1 for black men.

Mortality Due to Cardiovascular Disease

Cardiovascular diseases claimed 813,804 lives in 2007. On average, more than 2,200 Americans lose their lives to cardiovascular disease each day. Cardiovascular diseases are consistently ranked as the leading cause of death in the United States, exceeding all forms of cancer. The overall mortality rate (per 100,000) due to cardiovascular diseases was 251.2 in 2007; the rate for men was 300.3, and for women it was 211.6. More than 150,000 American deaths from cardiovascular disease in 2007 were persons under age 65; approximately one-third of cardiovascular deaths occurred before the age of 75. From 1997 to 2007, death rates from cardiovascular diseases declined 27.8 percent. Black individuals continue to experience substantially higher mortality rates than do other racial/ethnic groups (Roger et al., 2010). Table 2-1 presents data on mortality by gender and race/ethnicity.

Coronary Heart Disease

As the leading cause of death in America, CHD was responsible for 406,351 deaths, or one of every six, in 2007. Heart attacks were responsible for 132,968 deaths, and approximately 15 percent of those who have a heart attack will die from it, resulting in an average of 15 lost years of potential life. The annual incidence of sudden cardiac death is higher in men than women, but this difference begins to narrow with advancing age. Approximately 81 percent of individuals whose death is attributed to coronary heart disease are over age 65. Death rates from coronary heart disease decreased by 59 percent between 1950 and 1999, and decreased 26.3 percent between 1997 and 2007. CHD death rates vary by gender and race/ethnicity, as shown in Table 2-2.

TABLE 2-1 Mortality per 100,000 in 2007 Due to Cardiovascular Disease by Gender and Race/Ethnicity

	White	Black	Hispanic/Latino	American Indian/ Alaskan Native	Asian/Pacific Islander
Men	294.0	405.9	165.0	159.8	126.0
Women	205.7	286.3	118.0	99.8	82.0

SOURCE: Adapted from Roger et al. (2010).

TABLE 2-2 2007 Coronary Heart Disease Death Rates per 100,000 People by Gender and Race/Ethnicity

	White	Black	Hispanic/Latino	American Indian/ Alaskan Native	Asian/Pacific Islander
Men	165.6	191.6	122.3	112.2	91.7
Women	94.2	121.5	77.8	65.6	55.0

SOURCE: Adapted from Roger et al. (2010).

Stroke

Approximately 1 of every 18 deaths in the United States in 2007 was caused by stroke, resulting in 135,952 lives lost. It is also a leading cause of long-term disability. One American dies of a stroke about every 4 minutes. For individuals aged 45 through 64, 8 to 12 percent of ischemic strokes result in death within 30 days, and for hemorrhagic strokes the rate is 37–38 percent. The annual stroke death rate declined by 34.3 percent between 1997 and 2007, and the actual number of stroke deaths decreased by 18.8 percent. The 2007 death rate for stroke was 42.2 per 100,000. Table 2-3 provides data on stroke deaths by race/ethnicity.

More women than men die of stroke each year, with 60.6 percent of stroke deaths in 2007 occurring among women (Roger et al., 2010). Many states with high stroke mortality rates are concentrated in the southeast, which has become known as the "Stroke Belt" (HHS, 2006).

Hypertension

Hypertension claimed 57,732 lives in 2007. Between 1997 and 2007, the death rate from hypertension increased 9 percent and the actual number of deaths rose 35.6 percent. The overall death rate due to hypertension in 2007 was 17.8 per 100,000. However, there is tremendous disparity in the death rates for whites and blacks. The death rate for black males was 49.2, but only 15.7 for white males. Black females also suffer at much greater rates than white females—37 and 14.3, respectively.

Hypertension reduces life expectancy by 5.1 years for men and 4.9 years for women when compared with individuals of the same sex at age 50 who have normal blood pressure. Hypertension also increases mortality from heart disease and stroke; for every increase of 20 mmHg systolic and 10 mmHg diastolic, there is a doubling of mortality from these conditions (Roger et al., 2010).

Heart Failure

In 2007, 277,193 deaths from heart failure were reported, including 121,684 among men and 155,509 among women. Heart failure commonly occurs as an end result of other cardiovascular diseases such as coronary heart disease and long-standing hypertension, and is noted on one of every nine death certificates. The overall death rate for heart failure was 85.4 per 100,000 in 2007. Black males have the highest death rate due to heart failure (104.2) followed by white males (99.2), black females (82.5), and white females (76.7). Although survival following the onset of heart failure has improved over time, about half of individuals die within 5 years of a heart failure diagnosis (Roger, et al., 2010).

Costs of Cardiovascular Disease

The direct and indirect costs of cardiovascular diseases and stroke in the United States are estimated at more than $286 billion. This includes $167 billion in direct costs associated with physicians and other health professionals, hospital and nursing home services, medications, home health care, and medical durables as well as $119 billion in indirect costs resulting from lost productivity, illness, and death. The following estimated costs (direct and indirect) for various cardiovascular diseases in 2010 were reported by Roger and colleagues (2010):

TABLE 2-3 2006 Stroke Death Rates per 100,000 People by Gender and Race/Ethnicity

	White	Black	Hispanic/Latino	American Indian/ Alaskan Native	Asian/Pacific Islander
Males	41.7	67.1	35.9	39.8	25.8
Females	41.1	57.0	32.3	34.9	30.9

SOURCE: Adapted from Roger et al. (2010).

- Heart disease: $177.5 billion;
- Stroke: $40.9 billion;
- Hypertensive disease: $43.5 billion; and
- Other circulatory conditions: $24.6 billion.

Risk Factors

Cardiovascular disease is multifactorial; some risk factors are modifiable, and some (age, heredity, and male sex) cannot be modified. Among the modifiable risk factors for cardiovascular disease is a diet that is high in saturated fat and sodium. Other risk factors are tobacco smoke, high blood cholesterol, high blood pressure, physical inactivity, obesity and overweight, and diabetes mellitus. Stress and excessive alcohol consumption may also contribute to cardiovascular disease risk. This risk is higher among Mexican Americans, American Indians, native Hawaiians, and some Asian Americans, in part because of the higher rates of obesity and diabetes in these populations.

Cigarette smoking resulted in an estimated 443,000 premature deaths between 2000 and 2004; 32.7 percent of these deaths were related to cardiovascular disease in adults over age 35. Smokers experience a risk of developing coronary heart disease that is two to four times greater than individuals who don't smoke, and they have about twice the risk of stroke and 10 times the risk of peripheral vascular disease compared with nonsmokers. Secondhand smoke and smoking cigars or pipes can also increase the risk of heart disease (Roger et al., 2010). The *Healthy People 2010* target for smoking (12 percent or less) was achieved by only two states.

Elevated total blood cholesterol increases the risk of coronary heart disease, particularly in the presence of other risk factors such as high blood pressure and smoking. A person's cholesterol level is also affected by age, sex, heredity, and diet (AHA, 2010). NHANES data showed that from 2005 to 2008, approximately 33.5 million adults aged 20 and older had blood cholesterol levels ≥ 240 mg/dL. NHANES data from 1999–2006 showed that 8 percent of adults had undiagnosed hypercholesterolemia. Approximately one-third of individuals whose test results indicated high blood cholesterol or who were taking a cholesterol-lowering medication had not been notified by a health professional about their condition. Fewer than half of Mexican Americans with high cholesterol were aware of their condition, and blacks and Mexican Americans were less likely to be aware of their condition than were whites. Women were less likely than men to be aware that they had high cholesterol.

Physical inactivity is another risk factor for coronary heart disease. Moderate activity uses large muscle groups and is at least equivalent to brisk walking. Vigorous activity is rhythmic, repetitive physical activity that uses large muscle groups at 70 percent or more of the maximum heart rate for a person's age (HHS, 2010). Regular, moderate-to-vigorous physical activity helps prevent CVD and can improve blood cholesterol, hypertension, diabetes, and obesity. Data from the 2009 National Health Interview Survey showed that one-third of adults did not engage in daily leisure-time physical activity (light to moderate physical activity for at least 10 minutes). Furthermore, those data demonstrated that:

- 56 percent of adults (60.1 percent of women and 50.3 percent of men) reported no vigorous activity;
- 61.7 percent of American Indians/Alaskan Natives, 61.6 percent of blacks, 54.1 percent of whites, 61.4 percent of Asians, and 69.9 percent of Hispanic/Latinos reported not engaging in vigorous activity;
- 77.6 percent of individuals with less than a high school education, 66.2 percent with a high school diploma, 54 percent with some college, and 39.3 percent of respondents with a bachelor's degree or higher did not report engaging in any vigorous physical activity; and
- Fewer than half of adolescents (aged 14–17) met physical activity guideline recommendations of ≥ 60 minutes of moderate to vigorous activity on most days of the week.

Obesity is another risk factor for cardiovascular disease. Estimates from 2006 showed that about two-thirds of U.S. adults were overweight or obese; of these, more than a third—or 74 million—individuals were obese (AHA, 2009). Overweight for adults is defined as a body mass index (BMI) of 25 to 30, and obesity as a BMI of 30 or greater. Individuals who are obese or overweight are more likely to develop heart disease and stroke, even in the absence of other risk factors. Reducing weight by even 10 pounds can reduce the risk of cardiovascular disease (AHA, 2010). Overweight and obesity increase the risk of other CVD risk factors such as hypertension, hyperlipidemia, and diabetes. The age-adjusted relative risk for CVD is increased by about 20 percent in men and women who are overweight. Among those who are obese, the risk increases by 46 percent for men and 64 percent for women. NHANES data from 2003 to 2006 showed that nearly one-third of children and adolescents aged 2 to 19 years were at or above the 85th percentile of the 2000 BMI-for-age growth chart.

The World Health Organization (WHO) estimates that by 2015 the global burden of overweight will increase to 2.3 billion individuals, and obesity will increase to more than 700 million individuals. Obesity increases the risk of ischemic stroke in all racial and ethnic groups, and it was associated with 13 percent of all cardiovascular disease deaths in 2004. In addition to CVD, obesity is also associated with increased mortality due to some cancers, diabetes, and kidney disease. Furthermore, it can play a role in poor school performance, tobacco use, alcohol use, premature sexual behavior, and poor diet (Roger et al., 2010).

Diabetes, another risk factor, greatly increases the risk of cardiovascular disease, and approximately 75 percent of individuals with diabetes die from some form of cardiovascular disease (AHA, 2010). Adults with diabetes have heart disease death rates that are two to four times higher than rates in those without diabetes. NHANES data from 2005–2008 show that approximately 18 million adults had diabetes, 7 million had undiagnosed diabetes, and 81.5 million (37 percent of U.S. adults) had pre-diabetes (fasting blood glucose of 100 to < 126 mg/dL). American Indians have the highest prevalence of diabetes among all ethnic groups. Among the participants in the Strong Heart Study[1] ages 45–74 years, 70 percent of those in Arizona had diabetes as did 40 percent of those in Oklahoma and North and South Dakota (Lee et al., 1995). Non-Hispanic blacks and Mexican Americans experience a disproportionately high prevalence of diabetes when compared with non-Hispanic whites (Roger et al., 2010). The prevalence of diabetes rose substantially in the 1990s, increasing by 61 percent from 1990 to 2001, and it is expected to more than double from 2005 to 2050 (from 5.6 to 12 percent) in all age, sex, and race/ethnicity groups (AHA, 2009).

PREVENTION AND TREATMENT

Primary Prevention

National estimates of population changes in commonly accepted risk factors for CVD have, in general, demonstrated consistent improvements over the past several decades. However, increases in obesity and declining levels of physical activity are important exceptions to these trends. In an analysis published in the *New England Journal of Medicine*, Ford and colleagues (2007) reported that approximately half the decline in deaths from coronary heart disease among U.S. adults from 1980 through 2000 may be attributed to reductions in major risk factors, and half of the decline was attributed to evidence-based medical therapies. Specifically, they reported a 47 percent decrease attributed to treatments (secondary preventive therapies after myocardial infarction or revascularization, 11 percent; initial treatments for acute myocardial infarction or unstable angina, 10 percent; treatments for heart failure, 9 percent; revascularization for chronic angina, 5 percent; and other therapies, 12 percent). Changes in risk factors accounted for 44 percent of the decline (reductions in total cholesterol, 24 percent; systolic blood pressure, 20 percent; smoking prevalence, 12 percent; and physical inactivity, 5 percent). Risk factor reductions were partially offset by increases in BMI and the prevalence of diabetes, which accounted for an increased number of deaths (8 and 10 percent, respectively).

In December 2010, the U.S. Department of Health and Human Services released the goals, topics, and objectives for *Healthy People 2020* (healthypeople.gov). One of the 42 topics in *Healthy People 2020*, *Heart Disease*

[1] All participants in the Strong Heart Study are American Indians.

and Stroke, contains 24 objectives plus subobjectives aimed at improving "cardiovascular health and quality of life through prevention, detection, and treatment of risk factors for heart attack and stroke; early identification and treatment of heart attacks and strokes; and prevention of repeat cardiovascular events."[2] The recently released Institute of Medicine report *Leading Health Indicators for Healthy People 2020* (IOM, 2011) highlighted 24 objectives to be emphasized from among the nearly 600 *Healthy People 2020* objectives. Of those 24, 5 relate to cardiovascular disease or its risk factors. The objectives include:

- Reduce coronary heart disease deaths;
- Reduce the proportion of persons in the population with hypertension;
- Increase the proportion of adults who meet current federal physical activity guidelines for aerobic physical activity and for muscle-strengthening activity;
- Reduce the proportion of children and adolescents who are considered obese; and
- Reduce consumption of calories from solid fats and added sugars in the population aged 2 and older.

WHO has established similar priorities to reduce the incidence, morbidity, and mortality of cardiovascular disease. The aim is to effectively reduce cardiovascular disease risk factors and their determinants; develop cost-effective and equitable healthcare innovations for cardiovascular disease management; and monitor trends of cardiovascular diseases and their risk factors. The strategies that WHO identified for cardiovascular disease prevention include:

- Quitting tobacco use, reducing the amount smoked, or not starting the habit;
- Making healthy food choices;
- Being physically active; reducing BMI (to less than 25 kg/m2) and waist–hip ratio (to less than 0.8 in women and 0.9 in men, although these targets may differ by ethnic groups);
- Lowering blood pressure (to less than 140/90 mmHg);
- Lowering blood cholesterol (to less than 5 mmol/l or 190 mg/dl);
- Lowering LDL cholesterol (to less than 3 mmol/l or 115 mg/dl);
- Controlling glycemia, especially in those with impaired fasting glycemia and impaired glucose tolerance or diabetes (pre-diabetes); and
- Taking aspirin (75 mg daily) after ensuring blood pressure has been controlled.

WHO notes that these goals represent the minimum that should be achieved and that they are offered as broad guidance in managing cardiovascular risks. Individuals at high risk and those with established cardiovascular disease or diabetes may require more aggressive targets (WHO, 2007).

Kahn and colleagues (2008) investigated the effects of 11 nationally recommended prevention activities: providing aspirin to selected individuals, lowering LDL cholesterol in 4 subpopulations, lowering blood pressure in 2 subpopulations, lowering A1C in diabetic individuals, reducing fasting plasma glucose to < 110 mg/dl, smoking cessation, and reducing weight to BMI < 30 kg/m. Using data from NHANES, the investigators sought to determine the number and characteristics of U.S. adults aged 20–80 who are candidates for different prevention activities related to cardiovascular disease. They used the Archimedes model to simulate the U.S. population as well as a series of clinical trials that examined the effects of prevention activities over 30 years and compared the health outcomes, quality of life, and direct medical costs to current levels of prevention and care. They found that approximately 78 percent of U.S. adults aged 20–80 who are alive today are candidates for at least one of these prevention activities, and they concluded that myocardial infarctions and strokes would be reduced by 63 percent and 31 percent, respectively, if everyone received the interventions for which they are eligible. More feasible levels of performance would reduce myocardial infarctions by 36 percent and strokes by 20 percent. The investigators estimated that implementation of all prevention activities would add 221 million life years and

[2] See http://healthypeople.gov/2020/topicsobjectives2020/overview.aspx?topicid=21 (accessed August 2, 2011).

244 million quality-adjusted life years to the U.S. adult population over 30 years—an average of 1.3 years of life expectancy for each adult.

Kahn and colleagues (2008) found that the prevention activities associated with the greatest benefits to the U.S. population were providing aspirin to high-risk individuals; controlling pre-diabetes; weight reduction in obese individuals; lowering blood pressure in people with diabetes; and lowering LDL cholesterol in people with existing coronary artery disease. The investigators noted that these prevention activities are expensive, and smoking cessation was the only prevention strategy they found to be cost saving over 30 years. They concluded that aggressive application of nationally recommended clinical prevention activities could prevent a high proportion of coronary artery disease events and strokes that are expected to occur among U.S. adults. However, they cautioned that most clinical prevention activities will substantially increase costs if delivered in the current manner. Reducing cost and increasing efficiency in the delivery of prevention activities were recommended as a means to allow preventive strategies to achieve their potential.

Examining a different service delivery approach, the Task Force on Community Health Services (Soler et al., 2010) conducted a systematic review of selected interventions for work site health promotion and concluded that there was strong or sufficient evidence that assessment of health risks with feedback when accompanied by health education could reduce risk from tobacco use, alcohol use, seat belt nonuse, dietary fat intake, blood pressure, and cholesterol. They also found strong or sufficient evidence that this same intervention strategy could have significant effects on summary health risk estimates, worker absenteeism, and healthcare service use. Baicker and colleagues (2010) conducted a meta-analysis of work site wellness intervention studies and concluded that these programs can improve the health of employees and reduce healthcare costs by more than $3 for every dollar spent on wellness programs and reduce absenteeism costs by nearly the same ratio. They concluded that this return on investment suggests that the wider adoption of such programs could prove beneficial for budgets and productivity as well as health outcomes (Baicker et al., 2010).

Secondary Prevention

Screening for cardiovascular disease risk factors such as high blood pressure and high blood cholesterol are an important means of reaching individuals who may be unaware of their condition and referring them to appropriate care. For example, the Well-Integrated Screening and Evaluation for Women Across the Nation (WISEWOMAN) program provides screening and lifestyle interventions to low-income, uninsured, or underinsured women aged 40–64. The program is administered by the Centers for Disease Control and Prevention's (CDC's) Division for Heart Disease and Stroke Prevention, and it currently has 21 programs operating on the local level through states and tribal organizations. WISEWOMAN has reached more than 84,000 women and provided approximately 149,000 health screenings and 210,500 lifestyle interventions since the year 2000. These screenings identified more than 7,674 new cases of hypertension, 7,928 cases of high cholesterol, and 1,140 cases of diabetes (http://www.cdc.gov/wisewoman/about_us.htm).

Blood Pressure Management

The National High Blood Pressure Education Program (NHBPEP) was established in 1972 and is coordinated by NHLBI. NHBPEP is a cooperative effort among various professional and voluntary health agencies, state health departments, and community groups that use professional, patient, and public education strategies to reduce death and disability related to high blood pressure. The NHBPEP works to achieve the *Healthy People 2010* objectives for heart disease and stroke prevention by developing and disseminating educational materials and programs, and fostering partnerships among program participants.

The NHBPEP is also responsible for the publication of the *Report of the Joint National Committee on Detection, Evaluation, and Treatment of High Blood Pressure*, which provides guidelines and recommendations for clinicians and community organizations. The report was first published in 1976 and has been updated five times, most recently in 2003. The reports have been widely distributed: copies are sent to all state health departments as well as the majority of primary care clinicians and all hypertension control programs. Prior to the inception of

NHBPEP, less than one-quarter of Americans was aware of the relationships among high blood pressure, heart disease, and stroke. Hypertension awareness has increased to the point that three-quarters of Americans have their blood pressure checked every 6 months, and 90 percent have it checked every 2 years (NHLBI, 2010a).

Cholesterol

The National Cholesterol Education Program (NCEP) was established by NHLBI in 1985 to reduce the percentage of Americans with high blood cholesterol and resulting coronary heart disease. The program educates health professionals and the public about the risks of coronary heart disease associated with high blood cholesterol. Results from the NCEP Cholesterol Awareness Survey demonstrated that from 1983 to 1995, the percentage of the public who had ever had their blood cholesterol measured increased from 35 to 75 percent. The survey also demonstrated a trend toward pharmacologic intervention at lower cholesterol levels and widespread adoption of many NCEP guidelines for blood cholesterol detection and treatment. Data from NHANES III showed a decline in the reported intake of saturated fat, total fat, and cholesterol during the 1980s and 1990s. Average total blood cholesterol levels dropped from 213 mg/dL in 1978 to 203 mg/dL in 1991, and the prevalence of cholesterol of 240 mg/dL or higher declined from 26 percent in 1978 to 19 percent in 1991. Reductions in coronary heart disease mortality support the impact of NCEP's efforts at reducing high cholesterol (NHLBI, 2010b).

Obesity

The Obesity Education Initiative (OEI) was launched by NHLBI in 1991 to reduce the prevalence of overweight, obesity, and physical inactivity. The OEI educates professionals and the public about the risks associated with overweight and physical inactivity using two strategies: a population-based strategy and a high-risk strategy. The population approach works within the general population and promotes physical activity and healthy eating by partnering with community organizations such as elementary schools and public parks. Individuals at risk for complications associated with overweight and obesity are the focus of the high-risk strategy. The *Clinical Guidelines on the Identification, Evaluation, and Treatment of Overweight and Obesity in Adults: Evidence Report* (NHLBI, 2010c) was released in 1998 to provide federal clinical practice guidelines for overweight and obesity. The guidelines review the evidence supporting the recommendations and provide strategies for their implementation. They have been adapted for various audiences, including primary care physicians, nutritionists, nurses, pharmacists, health maintenance organizations, patients, and the public.

Diabetes

The National Diabetes Education Program (NDEP) was established in 1997 and is funded by the National Institutes of Health and the CDC. It includes more than 200 partners at the federal, state, and local levels working together to reduce diabetes and pre-diabetes by facilitating the adoption of proven approaches to prevent or delay the onset of diabetes and its complications. The NDEP uses culturally and linguistically appropriate diabetes awareness and education campaigns to increase knowledge of the seriousness of diabetes, its risk factors, and effective strategies for preventing complications associated with diabetes and preventing type 2 diabetes. The NDEP strives to increase the number of people who live well with diabetes, decrease the number of Americans with undiagnosed diabetes, promote effective lifestyle changes, reduce health disparities in populations disproportionately burdened by diabetes, and facilitate the incorporation of evidence-based research findings into healthcare practices.

Tobacco Control

The CDC's Office on Smoking and Health (OSH) was established in 1965 to reduce the death and disease caused by tobacco use and exposure to secondhand smoke. OSH created the National Tobacco Control Program (NTCP) in 1999 to encourage coordinated national efforts to reduce tobacco-related diseases and deaths. The program provides funding and technical support to state and territorial health departments. The components of

NTCP are population-based community interventions, counter marketing, program policy/regulation, surveillance, and evaluation. The goals of the program are to eliminate exposure to secondhand smoke, promote quitting among adults and youth, prevent initiation among youth, and identify and eliminate disparities among population groups (http://www.cdc.gov/tobacco/tobacco_control_programs/ntcp/index.htm).

Treatment and Intervention of Clinically Manifest Disease

The American Heart Association reports that between 1997 and 2007, the total number of inpatient cardiovascular operations and procedures increased 27 percent, from 5,382,000 to 6,846,000 annually. In 2007, an estimated 1,178,000 inpatient percutaneous coronary intervention procedures were done, and 232,000 patients underwent 408,000 coronary artery bypass procedures. In addition, 1,061,000 inpatient diagnostic cardiac catheterizations were performed (Roger et al., 2010).

Coronary Heart Disease

Particularly striking changes have taken place in the medical management of patients experiencing acute myocardial infarction (AMI) over the past several decades. In the early to mid-1980s, coincident with new insights into the pathophysiology of acute coronary disease, the medical management of AMI evolved from a strategy of watchful waiting and supportive therapeutic interventions to active treatment with aspirin, beta adrenergic blocking agents, thrombolytic therapy, and more recently, the angiotensin converting enzyme (ACE) inhibitors and antithrombotic regimens. Primary coronary angioplasty has been increasingly adopted as the main modality for reperfusion of the infarct-related coronary artery, in conjunction with the use of several adjunctive therapies. The American College of Cardiology and the AHA continue to disseminate and update on a regular basis evidence-based guidelines for the more effective management of patients with AMI with various cardiac medications, as well as for the use of coronary angioplasty in appropriately selected patients.

Despite impressive advances in the management of patients with AMI, limited evidence exists to demonstrate that physicians have uniformly adopted these treatment recommendations in the hospital or after discharge. Potential overuse of unproven or ineffective treatment regimens also may exist, though local surveillance data are not available to examine changing trends in physicians' management practices. Important differences in the management of hospitalized patients with AMI have been reported among countries, but most of these data are from the distant past. Trends in the use of cardiac procedures, stenting of the coronary arteries, newly developed interventional approaches, and other approaches yet to be incorporated into clinical practice need to be monitored.

Stroke

Carotid endarterectomy is the surgical procedure performed most frequently to prevent stroke. An estimated 91,000 inpatient endarterectomy procedures were performed in the United States in 2007 (Roger et al., 2010). The procedure is used to remove accumulated plaque from the carotid artery in the neck. Cerebral angioplasty can also be used to treat stroke by using balloons, stents, and coils to increase blood flow to the brain's vessels (AHA, 2010). Thrombolytic drugs such as tissue plasminogen activators (tPAs) help to dissolve clots that block blood flow to the brain. They are most effective when administered within 3 hours of stroke-onset symptoms. Complications can include brain hemorrhage, but tPA does not appear to increase the death rate in stroke patients when compared to placebo (National Stroke Association, 2011).

Hypertension

The Seventh Report of the Joint National Committee on the Prevention, Detection, Evaluation, and Treatment of High Blood Pressure (Chobanian et al., 2003) provides guidelines for hypertension treatment. The authors note that most hypertensive individuals over age 50 will achieve their diastolic blood pressure goal once systolic blood pressure is controlled; epidemiologic data support an emphasis on systolic blood pressure control. Lifestyle modi-

fications to lower blood pressure include weight management in those who are overweight or obese, a diet rich in potassium and calcium (e.g., the DASH diet), reduced sodium intake, increased physical activity, and moderation of alcohol consumption. Chobanian and colleagues note that a reduced sodium diet such as DASH is as effective as single drug therapy in controlling hypertension, and that two or more lifestyle modifications can yield even greater benefits. Drugs that have been shown to be effective in lowering blood pressure include ACE inhibitors, angiotensin receptor blockers, beta-blockers, calcium channel blockers, and thiazide-type diuretics. The Antihypertensive and Lipid Lowering Treatment to Prevent Heart Attack Trial (ALLHAT) demonstrated the effectiveness of diuretics in preventing the cardiovascular complications of hypertension. Diuretics are affordable and can enhance the antihypertensive efficacy of multidrug regimens, yet they remain underused (Chobanian et al., 2003).

Heart Failure

Treatment for heart failure depends on the severity of the condition, and it includes lifestyle changes, medications, and surgical intervention. Lifestyle modifications such as maintaining a healthful diet, drinking enough fluids, and controlling other risk factors (e.g., hypertension, diabetes, smoking, overweight, obesity) are recommended. Diuretics, ACE inhibitors, aldosterone antagonists, angiotensin receptor blockers, beta-blockers, isosorbide dinitrate/hydralazine hydrochloride, and digoxin are medications that may be prescribed to treat heart failure. A cardiac resynchronization therapy device or implantable cardioverter defibrillator may be indicated in cases of severe heart failure and heart damage. A mechanical heart pump may be used as a precursor to surgery or as a long-term treatment. Heart transplant is employed as a final life-saving measure for end-stage heart failure when other interventions have been unsuccessful. An estimated 111,000 inpatient implantable defibrillators and 358,000 pacemakers were inserted in the United States in 2007 (Roger et al., 2010), and 2,211 heart transplants were performed in 2009 (UNOS, 2010).

CONCLUSION

Substantial progress has been made in reducing CVD mortality rates. Even so, this group of diseases remains the leading cause of death in the United States. It also is a leading cause of morbidity and high costs. Of special concern is the disproportionately large burden of CVD on women, some minority groups, people living in certain geographical areas, and people with diabetes. This disparity exists to a great extent because the benefits of declining mortality trends have not been enjoyed by these population groups.

Considerable opportunity exists for further reducing CVD and its complications by improving and applying more widely the disease prevention and control strategies that are currently available, and also using more effective public health strategies. However, new and more effective disease control tools and strategies are also needed. Developing and implementing effective disease prevention and control strategies requires surveillance that tracks the burden of disease in the population; leads to hypotheses about etiologic factors that cause CVD; and provides information about the levels of modifiable risk factors across the entire population of the United States and within its various subpopulations. None of this can be accomplished without a more effective disease surveillance program.

To fully appreciate the burden of disease on the population, mortality rates, incident and recurrent event rates, disability rates, healthcare utilization patterns and rates, economic indicators, and other variables need to be measured and followed over time. Risk factors that need to be tracked include, but are not limited to, behaviors of individuals that generate or mitigate risk, and social, physical, and economic factors that either create risk or preserve health. The data sets that are created through systematic surveillance can, in turn, be used to explore hypotheses of etiology. Summarized by Labarthe (2011), "epidemiologic research with surveillance and program evaluation are required to fulfill the three core functions of public health: to assess the health status of communities and populations, develop policies that will foster conditions in which people can be healthy, and assure that these policies are being implemented with the intended benefits."

Population health is the ultimate goal of surveillance. Yet the epidemiology of CVD is complex and extends across patients and populations; primary, secondary, and tertiary prevention; advances in each domain of prevention; and clinical case management. The principal findings in several reports are that clinical recommendations and

guidelines are insufficient to change practice. Concerted efforts at the national and local policy levels are needed, including development of the necessary linkages among diverse sources of data and on methods to use data in an efficient and dynamic manner to effect evidence-based clinical and public health policy decisions.

Considerable opportunity exists for further reducing CVD and its complications by improving and applying more widely used prevention and control strategies. National and state data on the prevalence and distribution of CVD and relevant risk factors are available through major national surveys. Such information is important for making decisions about implementation strategies and programs needed for prevention of CVD at the national level and, to some extent, the state level. While these data are particularly useful for national and state decision making, national surveys do not generally have sufficient sample sizes to allow for local population units to understand the disease, risk factor, healthcare, and other important factors specific to their local setting. National surveys also may not measure the factors that are uniquely important in a particular subpopulation. Better local-level data would facilitate development of interventions aimed at the conditions that exist in the specific geographic area. The capability to collect local-level data is necessary to facilitate the development of interventions aimed at the conditions unique to specific geographic areas and specific subpopulations.

Registries, which are useful for obtaining information about individuals who have a particular disease or condition, provide information on incidence of CVD as well as numerous other clinical care data such as treatments, services provided, and follow-up information. Yet registry data do not accurately reflect the population with cardiovascular disease, only those who receive treatment and who are entered into the registry. Because vulnerable populations are less likely to have access to healthcare services, registry data most likely miss large elements of the population who experience the greatest disparities.

Major issues with both surveys and registries are the lack of standardized measures for collecting information and the inability to link data across sources. Of special concern is the persistent disparity in CVD patterns because the benefits of declining mortality trends have not proportionately helped women, some minority groups, certain geographical areas, or people with diabetes. Data gaps also exist in a number of areas: for example, timely and actionable local data are seldom available; data connecting use and cost patterns are hard to access; and data on emerging risk factors, conditions (e.g., atrial fibrillation, heart failure), and uptake of preventive and clinical services are rudimentary.

In summary, sources of data on CVD and its risk factors, largely from national surveys, exist, but there are a number of gaps: (a) the sources are disparate and a "system" that connects the various data sets does not exist; (b) while action is at the local level, data at such a level are lacking; (c) data are not sufficiently used in a dynamic manner to effect policy decisions; (d) greater flexibility and responsiveness of data systems are needed to accommodate rapidly changing population structures, demography, and scientific technological progress; and (e) greater integration of CVD and COPD surveillance is needed. Strengthening surveillance systems will enable timely and appropriate delivery of public health and clinical policy, and it will allow monitoring of trends in CVD risk factors and health status.

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3

Chronic Lung Disease

Chronic lung disease includes the conditions of chronic obstructive pulmonary disease (COPD), sleep-disordered breathing, and interstitial lung disease. This report has chosen to focus on COPD because it is the third leading cause of death in the United States (after heart disease and malignant neoplasms) (Kochanek et al., 2011) and is a substantial financial burden for the American economy. Many issues related to surveillance of COPD will apply equally to the other chronic lung conditions.

DEFINITION

Chronic obstructive pulmonary disease is an umbrella term for several conditions, including chronic bronchitis and emphysema as well as a subset of patients with asthma, that impede the flow of air in the bronchi and trachea. COPD has been defined as "a disease state characterized by airflow limitation that is not fully reversible. The airflow limitation is usually both progressive and associated with an abnormal inflammatory response of the lungs to noxious particles or gases" (Crapo et al., 2000; Rabe et al., 2007).

The heterogeneity of COPD has resulted in a variety of different definitions of disease that include components of destruction of the lung parenchyma (emphysema), chronic sputum production (bronchitis), limitation of airflow, and the development of hypoxemia. No single definition is perfect or all-inclusive. For example, some patients will have clinically significant emphysema in the absence of airflow limitation, whereas other patients may have significant airflow limitation in the absence of any emphysema or hypoxemia. In addition, lung function declines with age, resulting in questions about what represents disease versus normal aging. Although there is little debate surrounding moderate or severe disease, a great deal of debate surrounds more mild disease, which, ironically, is probably the most responsive to intervention.

One widely accepted and used classification strategy defines COPD by the presence of obstruction on spirometry: a forced expiratory volume in 1 second/forced vital capacity (FEV1/FVC) ratio of less than 70 percent, measured with a post-bronchodilator lung function (Celli et al., 2004b; WHO, 2008). Although this "fixed" ratio is easy to remember and simple, there is some concern that it may underestimate COPD in younger populations, overestimate it in older ones, and misclassify other patients (Celli et al., 2003; Kohler et al., 2003).

The GOLD and ATS/ERS criteria classify COPD into four stages (Celli et al., 2004b; WHO, 2008):

- Stage 1 (FEV1 ≥ 80 percent predicted);
- Stage 2 (FEV1 50 to < 80 percent predicted);
- Stage 3 (FEV1 30 to < 50 percent predicted); and
- Stage 4 (FEV1 < 30 percent predicted).

In addition, an "at risk" stage (formerly known as GOLD Stage 0) consists of patients with chronic respiratory symptoms (cough, sputum, or dyspnea) and normal lung function. Although this stage has been removed from the 2006 GOLD update because of data suggesting this stage may not progress to GOLD Stage 1 and higher COPD (Vestbo and Lange, 2002; WHO, 2008), people with symptoms and normal lung function have a lower quality of life and a higher risk of hospitalizations and mortality in follow-up investigations (Mannino et al., 2006; Stavem et al., 2006).

As noted above, this classification strategy may miss some patients with disease and overestimate the extent of disease in others. In addition, surveillance of disease typically depends on using information from administrative data sets, requiring the use of diagnostic and procedure codes to infer the presence of disease. This can be particularly problematic when looking at mortality related to COPD because most people with severe COPD who die have their death attributed to another cause (Mannino et al., 2006), and most people who die with a diagnosis of COPD listed on their death certificate do not have this attributed as the underlying cause of death. Therefore, the contribution of this chronic lung disease to observed mortality patterns and trends is underestimated.

EPIDEMIOLOGY

COPD is a common chronic disease. Most estimates of COPD place its prevalence in the adult population at 5 to 10 percent, although these estimates vary by the specific criteria used. Data from the Third National Health and Nutrition Examination Survey (NHANES III), the most recent national health survey that included spirometry, showed a prevalence of COPD in adults of 6.8 percent (Mannino and Buist, 2007). Over 50 percent of people with evidence of COPD have never been diagnosed with this disease. This proportion is even higher among people with mild disease, which is most amenable to intervention (Mannino and Braman, 2007).

COPD is responsible for about 700,000 hospitalizations annually in the United States. In recent years, the hospitalization rate among women has increased and is now similar to the rate among men. In 2009, more than 137,000 adults in the United States died from COPD (Kochanek et al., 2011). Age-adjusted mortality rates per 100,000 vary dramatically by state, from a low of 27.1 in Hawaii to a high of 93.6 in Oklahoma (CDC, 2008).

COPD has an enormous financial burden, with estimated direct medical costs in 1993 of $14.7 billion. The estimated indirect costs related to morbidity (loss of work time and productivity) and premature mortality is an additional $9.2 billion, for a total of $23.9 billion. By 2002 the direct and indirect costs were estimated at $32.1 billion (Mannino and Buist, 2007). The overwhelming risk factor for COPD is cigarette smoking. Other important risk factors include a history of asthma; occupational exposures to dusts, gases, vapors, and fumes; exposure to biomass smoke; and respiratory infections such as tuberculosis. In the developing world, exposures to biomass smoke and respiratory infections are particularly important (Buist et al., 2007). Comorbid diseases include cardiovascular disease, osteoporosis, lung cancer, and depression. In addition, diseases such as pneumonia and pulmonary hypertension are often complications of COPD (Decramer et al., 2008; Holguin et al., 2005).

PREVENTION AND TREATMENT

The classification of chronic respiratory disorders is often based on the pattern of physiologic impairment, either obstructive or restrictive, as measured with pulmonary function tests. Obstructive disorders, asthma, and COPD are the most common chronic respiratory diseases. The restrictive disorders are heterogeneous, including diffuse parenchymal lung diseases (e.g., idiopathic pulmonary fibrosis) and disorders that impair chest movement (e.g., morbid obesity, neuromuscular diseases). The focus of this review is on COPD, which provides an example of how surveillance throughout the life span may contribute to the prevention and control of chronic respiratory diseases.

While asthma and COPD are both characterized by airflow obstruction, asthma is reversible and COPD is incompletely reversible. Other differences also exist. For example, asthma most commonly develops in childhood, and COPD usually begins in the fifth decade or later. Moreover, recent evidence suggests that asthma and COPD have a number of distinct phenotypes with substantial overlap (Gibson and Simpson, 2009), and a number of childhood characteristics—including maternal asthma, paternal asthma, childhood asthma, respiratory infections, and maternal smoking—are risk factors for COPD (Salvi and Barnes, 2009; Svanes et al., 2010).

In adulthood there are multiple determinants of lung function level and decline (Gibson and Simpson, 2009), including cigarette smoking (Griffith et al., 2001), age, race, gender, bronchial hyperreactivity, asthma, occupational and environmental exposures, physical inactivity (Garcia-Aymerich et al., 2007; Pelkonen et al., 2003), chest wall deformity (DiBari et al., 2004), and psychological characteristics (Kubzansky et al., 2002).

Strategies for the prevention and control of asthma and COPD include methods for primary, secondary, or tertiary prevention. Primary prevention is accomplished by elimination of exposures that cause these diseases. Secondary prevention involves early detection and intervention among asymptomatic persons. Tertiary prevention is the management of symptomatic disease. *Healthy People 2020* has eight objectives related to asthma and four related to COPD.

Determining the effectiveness of these interventions requires surveillance throughout the life span to measure known risk factors, to conduct early detection, and to monitor outcomes. This chapter uses available data sources and evidence relevant to surveillance activities for COPD as an example of how to describe and evaluate the current state of surveillance, and to serve as background for recommendations on a national surveillance system.

Primary Prevention

While elimination of active smoking is the single most important intervention for the primary prevention of COPD in the United States, variation in the population-attributable fraction[1] for smoking suggests that other risk factors (described below) also have a significant public health impact. For example, Ezzati and Lopez (2003) examined the global burden of mortality from COPD. They estimated population-attributable fractions for COPD mortality among industrialized countries were 84 and 77 percent for men 30–69 years and ≥ 70 years, respectively. For women the corresponding estimates were 62 and 61 percent. Among developing countries, the estimates were substantially lower (49 and 45 percent for men, and 20 and 12 percent for women). Globally, the population-attributable fractions were 54 percent for men 30–69 years and 52 percent for men ≥ 70 years, and for women 24 percent and 19 percent, respectively.

Differences in population distributions of other COPD risk factors may partly contribute to variations in population-attributable fractions for smoking. These other factors may include occupational exposures, environmental tobacco smoke, other indoor air pollutants, outdoor air pollution, respiratory tract infections, asthma, low physical activity, poor nutrition, low socioeconomic/educational status, and genetic susceptibility. Moreover, interactions between smoking and these other factors may modify the magnitude of risk for COPD between populations (Hu et al., 2006; Svanes et al., 2010).

Compared to tobacco control, evidence is limited on effectiveness of controlling exposures to other risk factors for COPD, including maternal smoking and nutrition, early childhood exposure to tobacco smoke and infections, outdoor and indoor air pollution, occupational exposures, and other behavioral factors. Recent evidence suggests that maternal and early childhood interventions may offer opportunities at least as large as tobacco control for the prevention of COPD (Svanes et al., 2010). Lower levels of outdoor and indoor air pollution are associated with improved rates of lung growth in children (Avol et al., 2001; Gauderman et al., 2002), reduced rate of lung function decline in adults improved respiratory symptoms in adults (Downs et al., 2007; Menzies et al., 2006), and reduced mortality (Schindler et al., 2009).

[1] The population-attributable fraction "is the proportional reduction in population disease or mortality that would occur if exposure to a risk factor were reduced to an alternative ideal exposure scenario (e.g., no tobacco use)." See http://www.who.int/healthinfo/global_burden_disease/metrics_paf/en/index.html (accessed May 21, 2011).

Early Detection and Intervention

Airflow obstruction is common among asymptomatic persons (Mannino et al., 2000), and spirometry offers a feasible method for early detection and intervention to prevent or limit progression to symptomatic disease. An extensive review of available evidence concerning spirometry screening for COPD, conducted by the U.S. Preventive Services Task Force (USPSTF) and published in 2008, addressed eight questions (see Table 3-1) (Lin et al., 2008). While spirometry offers a feasible method for early detection and intervention, available evidence does not support the routine use of spirometry for screening. Results are inconclusive on the use of spirometry as a tool to enhance smoking cessation, and they are not available on the use of pharmacological treatments among asymptomatic persons with chronic airflow obstruction. A major limitation of spirometry screening is the low

TABLE 3-1 Questions and Conclusions on Screening for Chronic Obstructive Pulmonary Disorder (COPD) from U.S. Preventive Services Task Force

Question	Conclusion
Does screening for COPD with spirometry reduce morbidity and mortality?	No published controlled studies were found to address this question.
What is the prevalence of COPD in the general population? Do risk factors reliably discriminate between high-risk and average-risk populations?	About 1 in 14 adults in the general U.S. population has objectively measured airflow obstruction consistent with COPD. Airflow obstruction consistent with COPD is underdiagnosed in primary care. Basing a COPD diagnosis on symptoms alone leads to overdiagnosis. Older adults and current or past smokers are at increased risk for severe disease, but age and smoking status do not reliably discriminate between high- and average-risk populations.
What are the adverse effects of screening for COPD with spirometry?	No evidence suggests that spirometry causes any clinically significant adverse effects. A baseline percentage of false-positive results does occur in asymptomatic healthy persons.
Do individuals with COPD detected by screening spirometry have improved smoking cessation rates compared to usual smokers?	Evidence on spirometry as an independent motivational tool for smoking cessation is inconclusive because of a number of limitations.
Does pharmacologic treatment, oxygen therapy, or pulmonary rehabilitation for COPD reduce morbidity and mortality?	Most therapeutic trials have been restricted to patients with severe COPD, and none of the therapies have been tested in patients with airflow obstruction who do not recognize or report symptoms. Pharmacologic treatments modestly reduce exacerbations in patients with symptomatic severe COPD and may have a small absolute effect on all-cause mortality. Oxygen therapy reduces mortality in patients with very severe COPD and resting hypoxia. Pulmonary rehabilitation improves health status in selected patients.
What are the adverse effects of COPD treatments?	Minor adverse effects (oropharyngeal candidiasis, throat irritation, easy bruising, decreased bone density, dry mouth, urinary retention, urinary infection, sinus tachycardia, minor cardiovascular events) are commonly associated with inhaled COPD treatments. Evidence regarding major adverse events (cardiovascular events, fractures, and mortality) is mixed and inconclusive.
Do influenza and pneumococcal immunizations reduce COPD-associated morbidity and mortality?	Influenza vaccination reduces exacerbations in patients with COPD. Evidence regarding pneumococcal vaccination is insufficient. Data do not support prioritizing vaccination based on severity of spirometric impairment.
What are the adverse effects of influenza and pneumococcal immunizations in patients with COPD?	Both vaccines are well tolerated.

SOURCE: Lin et al. (2008).

prevalence of severe and very severe airflow obstruction (FEV1 < 50 percent predicted) in the general population, which is the group most likely to benefit from available medical interventions. Using COPD exacerbation as the primary health outcome, the USPSTF (Lin et al., 2008) estimated that among current smokers and never smokers, 833 and 2,000 persons, respectively, would have to be screened with spirometry to prevent one exacerbation over 6–36 months. The number needed to screen decreased with advancing age and was lowest among persons 70–74 years of age at 400.

While available evidence does not support the routine use of spirometry for screening, evidence from population-based and clinical studies (discussed in the next section) shows that diagnostic spirometry is underused and contributes to substantial diagnostic misclassification. Using NHANES III data, Mannino and colleagues (2000) found an overall prevalence of spirometry-defined obstructive lung disease of 8.5 percent, and an additional 4.3 percent of the population reported a diagnosis of obstructive lung disease, but did not have spirometric evidence. In a population-based household survey in England, Shahab and colleagues (2006) found spirometry-defined COPD among 13.3 percent of participants over 35 years of age, but only 18.8 percent of these volunteers reported any diagnosis of lung disease, which was lowest for mild impairment (6.4 percent) and increased with moderate (21.3 percent) and severe impairment (46.8 percent). Miravitlles and colleagues (2009) conducted a population-based survey in Spain and found an overall prevalence of spirometry-defined COPD of 10.2 percent, and of these patients only 26.9 percent reported a previous diagnosis of COPD, with 16 percent, 35.2 percent, and 85 percent for mild, moderate, and severe or very severe impairment, respectively.

Treatment of Diagnosed Disease

Management or tertiary prevention of COPD has the goals of reducing morbidity and mortality among persons with symptomatic COPD, and has been extensively described elsewhere (Rodriguez-Roisen et al., 2009). Four main components of management are diagnosis and monitoring, reduction of risk factors, management of stable COPD, and management of exacerbations (Rodriguez-Roisen et al., 2009). To raise awareness about the optimal management of COPD, a number of evidence-based guidelines have been developed in recent years (Celli et al., 2004a; National Collaborating Centre for Chronic Conditions, 2004; Rodriguez-Roisen et al., 2009). However, physician knowledge and adherence to these guidelines is limited, particularly among primary care physicians who provide the majority of care for patients with COPD (Barr et al., 2005; Rutschmann et al., 2004).

Diagnosis and Monitoring

This component of management refers to accurately diagnosing COPD, assessing disease severity and complications, and diagnosing comorbid conditions. Furthermore, as a chronic progressive condition, COPD requires ongoing monitoring for diagnosis and treatment of complications and comorbid conditions. While spirometric evidence of "airflow limitation that is not fully reversible" (Rodriguez-Roisen et al., 2009) is the hallmark for diagnosing COPD, clinicians infrequently use spirometry and most often diagnose chronic lung diseases based solely on respiratory symptoms and current or past cigarette smoking (Han et al., 2007; Joo et al., 2008a).

Severity and complications In addition to the findings on spirometry, which is used to classify the severity of airflow obstruction, a number of other factors influence the prognosis of patients with COPD. These factors include age, severity of dyspnea, body mass index (BMI), 6-minute walk distance (Celli et al., 2004a; Puhan et al., 2009c), and complications (e.g., hypoxemia, hypoventilation, right heart failure). Although awareness of these factors may be used to tailor management practices, limited evidence is available about the effectiveness of their use in clinical practice. One example is undertreatment of hypoxemia, with only 32 percent of patients with baseline hypoxia receiving home oxygen as part of routine management (Mularski et al., 2006).

Comorbid conditions Patients with COPD frequently have other illnesses with similar symptoms. This may further contribute to diagnostic misclassification and may affect prognosis and management (Schneider et al., 2010a). On average, persons aged 65 and older have three or more chronic conditions (Boyd et al., 2005), and patients with

COPD also commonly have cardiovascular disease, lung cancer, depression, cognitive impairment, osteoporosis, and gastroesophageal reflux (Hung et al., 2009; Rascon-Aguilar et al., 2006; Schneider et al., 2010a,b; Sin et al., 2006; Soriano et al., 2005). The co-occurrence of multiple chronic illnesses presents a number of diagnostic and management challenges. Delay in diagnosis of COPD or cardiovascular disease may result because of the non-specificity of respiratory symptoms. The use of many different medications to treat multiple conditions may contribute to adverse drug interactions (Boyd et al., 2005). Moreover, polypharmacy combined with underlying depression and cognitive impairment may cause problems with medication adherence. Identification of single or combined treatments for two or more conditions offers a potential solution to polypharmacy. Targeting chronic systemic inflammation, a common pathophysiological pathway between COPD and cardiovascular disease, offers the potential for a common therapeutic agent. For example, limited evidence suggests that the use of statins to treat systemic inflammation reduces morbidity and mortality in patients with COPD (Alexeeff et al., 2007; Frost et al., 2007; Keddissi et al., 2007; Søyseth et al., 2007; van Gestel et al., 2009). Addressing the clinical challenges of comorbid illnesses in patients with COPD is an ongoing area of investigation.

Reduce risk factors Smoking cessation is a critical component in the management of patients with COPD. Cessation is associated with reduced rate of decline in lung function, improved symptoms, and lower mortality (Anthonisen et al., 2005a; HHS, 2004). The comparative effectiveness of smoking cessation interventions among patients with COPD was recently examined by Strassmann and colleagues (2009), who conducted a meta-analysis of eight clinical trials that included 7,372 patients. Overall, smoking cessation counseling combined with a pharmacological agent (i.e., nicotine replacement, antidepressant) had the greatest benefit compared to counseling alone or to usual care. High-intensity counseling combined with nicotine replacement had the greatest success when compared to usual care (OR = 5.22; 95 percent CI, 4.43–6.15). By contrast, low-intensity counseling without a pharmacological agent compared to usual care had no significant effect (OR = 1.17; 95 percent CI, 0.39–3.54). All other combinations of counseling and pharmacological agents had intermediate effects.

Compared to smoking cessation, evidence is limited on the effectiveness of controlling exposures to other risk factors for COPD-related morbidity and mortality, including outdoor and indoor air pollution, occupational exposures, and nutrition (e.g., BMI). However, control of outdoor and indoor particulate pollution may have a number of benefits for patients with COPD, including reduced rate of lung function decline (Downs et al., 2007; Menzies et al., 2006), improved chronic respiratory symptoms (Menzies et al., 2006; Schindler et al., 2009), and reduced mortality (Goodman et al., 2007; Pope et al., 2009).

Management of stable COPD Strong evidence suggests that the management of patients with COPD is often suboptimal and many patients are undertreated (Barr et al., 2005; Mularski et al., 2006). The optimal management of patients with COPD is composed of self-management education, medications, influenza/pneumococcal vaccination, and pulmonary rehabilitation (Rodriguez-Roisen et al., 2009; Wilt et al., 2005). Each of these components of routine care is reviewed below.

Self-management education refers to the process of informing, motivating, and preparing patients to control their disease and improve their health status through medical treatments and health behavior change (Bourbeau et al., 2004; Epping-Jordan et al., 2004). Available evidence suggests gaps in patient knowledge for effective self-management (Barr et al., 2005; Hernandez et al., 2009). Self-management programs have been part of center-based pulmonary rehabilitation programs (Troosters et al., 2005) and stand-alone programs (Effing et al., 2007; Shahab et al., 2006), with three main components: (1) lifestyle change (e.g., smoking cessation, exercise, nutrition); (2) dyspnea management (e.g., medication adherence/inhalation technique, breathing technique, energy conservation, relaxation); and (3) exacerbation action plan. Because programs often target more than one of these topics, the relative importance of each component is unknown. Overall, results of self-management programs in settings other than pulmonary rehabilitation have demonstrated limited benefit, probably because of methodological issues (e.g., patient selection, small sample size) and variation in the quality of the interventions (Effing et al., 2007; Monninkhof et al., 2003; Shahab et al., 2006). Most programs have emphasized patient education, which is not effective for changing health-related behavior (Nieuwenhuijsen et al., 2006). Limited attention has been given to theory-based health behavior interventions that address not only patient knowledge but also motivation

and behavioral support (Effing et al., 2007; Shabab et al., 2006). Moreover, while self-management interventions may be necessary for improving outcomes, results are inconsistent and alone may be insufficient for improving quality-of-life or healthcare use among patients with COPD.

A growing literature strongly suggests that a number of psychosocial factors have a wide-range of influence on functional and health status among patients with COPD (Katz et al., 2010; Simpson and Rocker, 2008). For example, depression, cognitive impairment, self-efficacy, and social support may all affect adherence to medical management of COPD, and subsequent functional and health status (Antonelli-Incalzi et al., 2007; Bourbeau et al., 2004; Davis et al., 2006; Wong et al., 2005).

Medication management The cornerstone of medical management has been the use of inhaled medications, including short- and long-acting bronchodilators and anti-inflammatory agents. Both classes of medications provide symptom relief, improve quality of life, and decrease exacerbations in selected patients (Wilt et al., 2007). However, a number of factors may contribute to suboptimal use of medications, including lack of physician knowledge (Rutschmann et al., 2004), underuse (Anthonisen et al., 2005b; Joo et al., 2008a), poor adherence, and the fact that even under ideal circumstances, fewer than half of the patients in randomized trials benefit from potent pharmacological interventions (e.g., tiotropium) (Vincken et al., 2002). These observations may partly explain the finding that fewer than 60 percent of patients with COPD receive recommended medications (Mularski et al., 2006). Among 21,529 Medicare beneficiaries with obstructive lung disease, the majority of whom had COPD, Craig and colleagues (2008) found that only 30.8 percent received some form of pharmacotherapy. Similarly, Bourbeau and coworkers (2004) found that only 34 percent of patients in primary care settings received medications consistent with guideline recommendations, and the patterns of treatment inconsistency included both under- and overtreatment. While the use of medications increases with the severity of COPD impairment, both under- and overtreatment have been described in a number of investigations (Anthonisen et al., 2005b; Chavez and Shokar, 2009; Craig et al., 2008; Diette et al., 2010; Jones et al., 2008; Joo et al., 2008b; Miravitlles et al., 2008).

Influenza and pneumococcal vaccination The use of these vaccinations in the management of patients with COPD has been reviewed extensively elsewhere (Mannino et al., 2000). Briefly, influenza vaccination reduces exacerbations in patients with COPD, but the evidence regarding pneumococcal vaccination is insufficient (see Table 3-1). Moreover, data do not support prioritizing vaccination based on severity of spirometric impairment.

Pulmonary rehabilitation Compared to the healthy elderly, patients with COPD are markedly inactive (Pitta et al., 2005). This inactivity from dyspnea leads to deconditioning and further decline in functional performance, which, in turn, may lead to social isolation, poor quality of life, and depression. The available evidence strongly suggests that disruption of this cycle of physical inactivity and deconditioning is necessary to substantially improve functional performance and health status for patients with COPD. Pulmonary rehabilitation programs have been designed to address this problem and are cost-effective (American Thoracic Society, 1999; Griffiths et al., 2001; Lacasse et al., 2006).

However, despite the available evidence on the benefits of pulmonary rehabilitation, surveys conducted in the United States, United Kingdom, and Canada have consistently estimated that fewer than 2 percent of patients with COPD receive pulmonary rehabilitation (Bickford et al., 1995; Brooks et al., 2007; Yohannes and Connolly, 2004).

Manage exacerbations Patients with COPD suffer from chronic respiratory symptoms, including dyspnea, cough, and fatigue, and frequently have episodic acute worsening of their symptoms that may require an escalation of medical therapies and, in severe episodes, emergency room treatment or hospitalization. In a cohort of 198,981 U.S. veterans with COPD, Joo and colleagues (2007) used inpatient, outpatient, and pharmacy databases to identify all exacerbations and found that 44 percent had at least one exacerbation or more over a 2-year follow-up period. Moreover, the rate of exacerbations varied widely between regions, ranging from 0.34 to 0.75 exacerbations per person per year, which may be underestimates because patients underreport episodes of exacerbation (Xu et al., 2010). Of all exacerbations, about 15 to 40 percent are severe enough to result in an emergency room visit or hospitalization (FitzGerald et al., 2007; Oostenbrink et al., 2004; Xu et al., 2010). A number of factors have been associated with hospitalization for a COPD exacerbation, including lower socioeconomic status (Disano et al., 2010), interruption of health insurance coverage (Bindman et al., 2008), and fewer primary care visits (Kronman et al., 2008). Clinical predictors associated with hospitalization for COPD exacerbation have included older age,

comorbidity, chronic oxygen therapy, lower FEV1, hypoventilation, hospitalization in previous year, greater number of respiratory medications prescribed, regular use of corticosteroids, and depression (Bahadori and FitzGerald, 2007; FitzGerald et al., 2007; Xu et al., 2008).

Findings by Laditka and Laditka (2006) demonstrated that hospitalization for an exacerbation of COPD is considered preventable and a marker for suboptimal access to or effectiveness of primary care, also known as an ambulatory sensitive condition. Using a nationwide sample of community hospital discharge data, the researchers found that compared to non-Hispanic whites, African American males (adjusted relative rates of 1.9 and 1.6 for ages 19–64 and 65+, respectively) and Hispanic males (2.6 and 2.3, respectively) and females (1.6 and 2.1, respectively) had higher rates of hospitalizations for COPD, adjusted for disease prevalence. In an analysis of admission rates in North Carolina among Medicare beneficiaries for ambulatory-care sensitive conditions including COPD, Howard and colleagues (2007) found that African Americans had lower admission rates for COPD compared to whites (OR = 0.67, 95 percent CI 0.65–0.69). Population and methodological differences may partly explain the conflicting results between these two studies.

Disease exacerbations, whether reported or not, substantially impact patients' health status, including morbidity and mortality. Reductions in quality of life have been found after exacerbations for up to a year after an exacerbation. While the greatest reductions are among patients with more severe reported exacerbations, even patients who do not report their worsening symptoms have clinically significant declines in quality of life (Xu et al., 2010). In addition to the impact of exacerbations on quality of life, these episodes are associated with increased mortality (Agabiti et al., 2010). While a number of factors may contribute to variation in outcomes after an exacerbation, this remains an area of active investigation, with a focus on quality of care provided during an exacerbation.

Lindenauer and colleagues (2006) analyzed clinical data from 69,820 patients hospitalized for an exacerbation at 360 U.S. hospitals. They compared actual treatment to recommended management guidelines developed by the American College of Physicians and the American College of Chest Physicians, and found that 66 percent received all five components of recommended care (i.e., chest radiography, supplemental oxygen, bronchodilators, systemic corticosteroids, and antibiotics); 45 percent received at least one non-recommended measure (i.e., acute spirometry, methylxanthine bronchodilator, sputum testing, mucolytic therapy, or chest physiotherapy); and only 33 percent received ideal care (i.e., all five recommended and none of the non-recommended measures). In a recent analysis of this same database that included 84,621 patients with a COPD exacerbation, Rothberg and colleagues (2010) found that antibiotic use was associated with a decreased risk (odds ratio [OR] 0.87; 95 percent confidence interval [CI], 0.82–0.92) of treatment failure (i.e., mechanical ventilation, inpatient mortality, and readmission). Furthermore, treatment failure was no more likely with low-dose oral compared to high-dose intravenous corticosteroids (OR = 0.93, 95 percent CI, 0.84–1.02) (Lindenauer et al., 2010). In addition to the quality of COPD-specific management potentially affecting outcomes of COPD exacerbations, outcomes may also be adversely affected by comorbid conditions and associated complications. Diastolic dysfunction is associated with more frequent and prolonged exacerbations in patients with COPD (Abusaid et al., 2009). Moreover, following an exacerbation patients are at increased risk for myocardial infarction within 1–5 days (OR = 2.27; 95 percent CI, 1.1–4.7) and stroke within 1–49 days (OR = 1.26; 95 percent CI, 1.0–1.6) (Donaldson et al., 2010).

Because of the morbidity and mortality associated with exacerbations, there has been growing interest in prevention and early recognition and control of exacerbations. A number of methods to prevent or limit exacerbations have been examined, including pharmacological measures, self-management education, pulmonary rehabilitation, and control of exposures that cause exacerbations. To examine the comparative effectiveness of four categories of inhaled medications for preventing exacerbations, Puhan and colleagues (2009a) conducted a meta-analysis of 35 clinical trials with 26,786 patients. Overall, all categories of inhaled medications decreased the risk of exacerbation by 29 percent compared to placebo (OR = 0.71; 95 percent CI, 0.64–0.80), and when compared to long-acting beta-agonists alone, there were no differences with long-acting anti-cholinergic, corticosteroids, or combination long-acting bronchodilators and corticosteroids. However, when the FEV1 percent predicted was less than 40 percent, these three categories of inhaled medications significantly decreased the risk of exacerbation compared to long-acting beta-agonists alone. In an observational study of managed-care Medicare beneficiaries, Simoni-Wastila and colleagues (2009) examined inhaled medication use on COPD-related hospitalizations and emergency department visits. They found that a combination long-acting bronchodilator and corticosteroid was

more effective when compared to anticholinergic treatments in decreasing emergency department visits (OR = 0.82; 95 percent CI, 0.76–0.89) and hospitalizations (OR = 0.82; 95 percent CI, 0.75–0.89).

In addition to inhaled medications for COPD, treatment of comorbid conditions may also prevent exacerbations. The cardioprotective benefits of beta-blockers may explain the recent observation that chronic use of these medications decreases the risk of exacerbations of COPD (OR = 0.71; 95 percent CI, 0.60–0.83) and mortality (OR = 0.68; 95 percent CI, 0.56–0.83) (Rutten et al., 2010).

Integrated care models Integration of the necessary management components for providing optimal delivery of health care to patients with chronic illnesses presents many challenges and has been an active area of investigation (Peikes et al., 2009). Results from a large, multicenter randomized trial of care coordination programs among more than 18,000 Medicare beneficiaries—which included patients treated for such common chronic conditions as coronary artery disease (60.5 percent), congestive heart failure (48.3 percent), diabetes (39 percent), COPD (32.1 percent), cancer (20.8 percent), and stroke (13.5 percent)—showed no overall reduction in hospitalizations, improvement in quality of care, or reduction in healthcare costs. However, results from selected programs in the trial suggested potential program characteristics (e.g., in-person contact between care coordinators and patients, close collaboration between the care coordinator and patient's physician) that may be helpful for the design of future programs (Ayanian, 2009).

In addition to generic care coordination programs for chronic illness, a number of COPD-specific programs have been investigated to address the complexities of COPD management through better integration of care, including delivery system design, decision support, and clinical information systems. In a systematic review of 32 studies, Adams and colleagues (2007) did not find improvements in symptoms or quality of life with any of the interventions, but did find statistically significant improvements in emergency/unscheduled visits and hospitalizations when two or more of the components were used. Peytremann-Birdevaux and colleagues (2008) reviewed 13 studies of disease management defined as an intervention that "included two or more different components (e.g., physical exercise, self-management, and structured follow-up), two or more health professionals actively involved in patient care, patient education was considered, and at least one component of the intervention lasted a minimum of 12 months." Overall, disease management was associated with improved quality of life, lower risk of hospitalization, and improved exercise capacity.

ROLE OF SURVEILLANCE

Although there have been a number of investigations of outcome-specific data for COPD, there is no U.S. surveillance system that is characterized by data collection, analysis, and interpretation that is ongoing and systematic. Apart from the use of vital statistics for describing mortality from COPD, the use of other data sources to examine COPD-specific outcome data has been a relatively recent phenomenon. Moreover, concerns about the available outcome measures and data limitations (discussed in greater detail below) may contribute to delays in progress (Heffner et al., 2010). Therefore, there has been limited time for dissemination and consensus about results, with little opportunity to link these results to planning, implementation, and evaluation of public health and clinical programs to improve COPD prevention and control.

Data relevant to surveillance of COPD are currently available from a number of national and international sources. In the United States, these sources include vital statistics (Lewis et al., 2009), hospital data reporting (http://www.healthgrades.com; Lindenauer et al., 2006), Medicare (Wennberg et al., 2004; http://www.hospitalcompare.hhs.gov), Medicaid (Bindman et al., 2008), Veterans Administration (Joo et al.. 2007, 2008a; Singh, 2009), population-based surveys (Mannino et al., 2000), and health insurance claims databases (Mapel et al., 2006; McKnight et al., 2005). Examples of international sources of COPD surveillance have been published from meta-analyses of clinical trials (Puhan et al., 2009a,b; Strassmann et al., 2009), the U.K. General Practice Research Database (Khan et al., 2010; Levy et al., 2007; Smith et al., 2008; Soriano et al., 2001), and health administrative data in Canada (Gershon et al., 2009).

Available evidence supports the feasibility of these data sources for surveillance and suggests potential opportunities for their use to guide public health policy and other interventions to improve various components

of prevention and healthcare delivery for COPD. For example, Wennberg and colleagues (2004) used Medicare claims data for more than 90,000 patients with COPD, congestive heart failure, and cancer to examine patterns of care at the hospital level, including length of stay, intensive care unit (ICU) days, and physician visits. They found wide variation in healthcare use, ranging from 2.9 to 7.3 times the number of hospital or ICU days used between the lowest and highest use hospitals, respectively. These results suggest the potential for large opportunities to improve efficiency of care.

A number of other recent examples show potential uses of these data sources in a surveillance system for COPD. U.S. examples include:

- use of state Medicaid claims data to identify COPD patients with high healthcare use to target for case management (Yarger et al., 2008),
- use of Medicare claims to identify patient and physician characteristics associated with potentially preventable hospitalizations (O'Malley et al., 2007),
- use of Medicare managed-care data to examine cost of illness and comorbidities (Menzin et al., 2008) and monitoring trends in quality-of-care and healthcare disparities (Trivedi et al., 2005),
- use of Medicaid (Rascati et al., 2007) and Medicare managed-care (Simoni-Wastila et al., 2009) claims data to examine comparative effectiveness of different inhaled medications for COPD,
- voluntary reporting of hospital data for comparative effectiveness research of corticosteroid dose and route of administration during exacerbation of COPD (Lindenauer et al., 2010), and
- use of data on variations in preventable hospitalization rates for COPD and other chronic conditions to target continuing medical education topics (Sumner et al., 2008).

International examples of surveillance activities relevant to COPD have been conducted to monitor quality of primary care and drug safety. In the United Kingdom, the Health Improvement Network was used to demonstrate improvement of spirometry use and combination inhaler use among primary care physicians after release of management guidelines and pay-for-performance incentives (Smith et al., 2008). In another analysis using data from 7,456 general practices in the United Kingdom, higher levels of nurse staffing were associated with improved performance on a number of clinical performance measures for COPD, coronary heart disease, hypertension, and diabetes (Griffiths et al., 2010). Furthermore, surveillance has been conducted to monitor the safety of pharmacological treatments for COPD, albeit with conflicting results (Jara et al., 2007; Johansson et al., 2010; Lee et al., 2008, 2009; Loke et al., 2010; Pujades-Rodriguez et al., 2007; Salpeter, 2009).

A major goal of surveillance is to promote interventions for the prevention and control of COPD, and to evaluate the effectiveness of these interventions through ongoing surveillance of various process and health outcomes. This process may happen at the national, regional, and local levels. Although hospitals do not report quality-of-care indicators for COPD to the Joint Commission and the Centers for Medicare & Medicaid Services—they do for acute myocardial infarction, heart failure, and pneumonia—limited evidence suggests that such reporting, with quarterly feedback on performance to hospitals, has been associated with performance improvement (Jha et al., 2005; Williams et al., 2005). Despite the lack of national reporting, the reporting and feedback process for other diseases may be contributing to a growing interest in local performance improvement initiatives for COPD (Deprez et al., 2009; Roberts et al., 2009).

While a number of data sources for surveillance of COPD are available as discussed above and throughout the chapter, there is no comprehensive surveillance system that contributes to the prevention and control of COPD. Except for the COPD optional module in Behavioral Risk Factor Surveillance System (BRFSS) and some data collected by NHANES, most available data sources have been one-time investigations and are not part of a larger system that is ongoing. However, because these data sources provide evidence of the feasibility and potential usefulness for enhanced surveillance and decision making, they could serve as the basis for developing a system of COPD surveillance. A summary of the current state of surveillance relevant to the primary, secondary, and tertiary prevention of COPD follows.

In terms of primary prevention, cigarette smoking is the major risk factor for COPD. This factor is regularly monitored population-wide through the BRFSS. However, there is no population-based monitoring of other risk factors for COPD such as occupations that expose workers to high levels of dust.

Identifying individuals early in the course of their disease is important to secondary prevention efforts. Although current evidence suggests that widespread screening with spirometry is not effective, this nevertheless remains an important consideration. An analogy to the cardiovascular diseases is identification of increased cholesterol levels, which predict cardiovascular disease. These elevated levels can be followed and targeted for specific interventions. COPD does not, at this point, have such a biomarker available, although several candidates, such as C-reactive protein, fibrinogen, and radiographic changes, are currently being investigated. Filling this gap would result in a better understanding of disease progression and give an additional means of monitoring progression, both in individuals and the population. This may become more important in future years as the prevalence of smoking decreases and the other risk factors for COPD become more important.

The major gap in the surveillance of COPD for tertiary prevention is the lack of pulmonary function data in most databases, which contributes to misdiagnosis. When these data do exist, they may not be accessible or may be in a format that is not easily usable in surveillance activities. Moreover, the underutilization of spirometry in the diagnosis of COPD results in sub-optimal management. To address this gap, the Center for Medicare and Medicaid Services has proposed spirometry evaluation as an indicator of quality of care for patients with a diagnosis of COPD, along with bronchodilator therapy based on FEV1 level and smoking cessation counseling (Berwick, 2011). This policy should contribute to an improvement in the current gaps in diagnosis and management of patients with COPD.

Another gap is the lack or heterogeneity of other objective measures of COPD, such as imaging information, that can better define the presence of bronchial wall thickening or emphysema and are predictors of poor outcomes. Current studies, such as COPDGene, MESA COPD, and Spiromics, will be addressing the scientific aspect of these gaps, such as what may be the best imaging measures to follow over time. Additional studies are needed to assess whether these measures can be routinely used in the clinical evaluation of patients. Filling these gaps would result in a better picture of the true burden of disease and how COPD relates to morbidity and mortality in the population.

The available evidence provides strong support for the feasibility and potential usefulness of a national surveillance system for COPD. A number of limitations, however, need to be considered and addressed to fully realize the benefits of surveillance. As previously discussed, the diagnosis of COPD is under- and overdiagnosed, which limits the usefulness of diagnostic codes from administrative data. While the specificity of diagnostic algorithms show promise for selected applications (Mapel et al., 2006; Yarger et al., 2008), their sensitivity and positive predictive value for COPD are low (Rector et al., 2004; Singh, 2009). Moreover, variations in patterns of diagnostic practices may further bias claims data (Song et al., 2010). A major gap in the surveillance of COPD is the relative paucity of and scant evidence for the effectiveness of COPD-specific performance measures that are currently in use (Heffner et al., 2010). For example, Medicare process performance measures are not strongly associated with hospital risk-adjusted mortality rates (Werner and Bradlow, 2006).

In summary, while components of a surveillance system for COPD are available in the United States and have provided evidence of the need for improvement of the prevention and control of COPD, the committee concluded that further development is needed to create an effective surveillance system. Such development will require the participation of experts from a variety of disciplines to address the important limitations described above. Effectiveness will be determined by the quality of the data; the ongoing, systematic collection, analysis, and interpretation of the data; and the ongoing use of the results to plan and implement prevention and control interventions. None of these characteristics currently exist in the United States for the surveillance of COPD. As previously discussed, the quality of data needs to be improved, with standards for diagnosis to minimize diagnostic misclassification and better COPD-specific outcome data (Heffner et al., 2010). While a number of data sources have been used to examine outcomes, most analyses conducted to date have been one-time studies, and there is no structured or systematic use of these sources for ongoing analyses. Finally, health policy advocates and federal and private institutions in the United States need more well-defined organizational structures and processes for disseminating and using the results from chronic disease surveillance in order to enhance the prevention and control of COPD.

The focus of this chapter has been on COPD, yet the same kinds of data (e.g., those related to risk factors, screening, environmental exposures, availability of care, access to care, patient education, treatments, quality of life, etc.) are needed for other chronic lung diseases, including asthma. In fact, collection of these data on asthma, for example, could lead to improved understanding of the relationship between asthma and COPD. This has

important implications not only for improved understanding of the pathophysiology of both diseases but also for improved understanding of corresponding health disparities. An effective surveillance system that encompasses chronic lung disease more broadly could enhance efforts aimed at prevention, diagnosis, treatment, and improved health outcomes.

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4

Health Disparities

Disparities in health and health care may be found at each step along the continuum of chronic disease, from primary prevention to disease management. To identify and understand these disparities, a surveillance system must be able to provide data to analyze disparities in incidence and prevalence, morbidity and mortality, functional health outcomes, primary and secondary prevention approaches, risk factors, and healthcare delivery. This system must function not only at the national level but also at the regional, state, and local levels. The system should be effective in monitoring populations defined by race and ethnicity, gender, age, income, education, social and physical environments, and geographic factors such as birthplace and years of residence in the United States.

A contemporary national framework for the surveillance of cardiovascular disease (CVD) and chronic obstructive pulmonary disease (COPD) can drive the development of policies and programs at the local level that help to ensure high-quality effective preventive and therapeutic programs for the entire U.S. population. Much of our knowledge of racial and ethnic disparities has been derived from national population samples, but efforts to eliminate health disparities must occur in collaboration with local and regional healthcare organizations, communities, healthcare institutions, and healthcare providers. Federal databases are the source of much of the information currently available on racial and ethnic health disparities (Sequist and Schneider, 2006). Although the federal government will remain a major source of data on racial and ethnic health and healthcare disparities, linkage to Census data, vital statistics, household surveys, small area data, administrative data, and data from local groups and healthcare organizations should be an integral part of the national surveillance system.

WHY SHOULD HEALTH DISPARITIES BE MEASURED?

In *Healthy People 2010*, the federal government established two major goals for health promotion and disease prevention: (1) to increase life expectancy and improve quality of life; and (2) to eliminate health disparities (HHS, 2000). *Healthy People 2010* made the elimination of health disparities one of the highest priorities of the federal government (Satcher, 2010). Many of these contemporary health disparities in the United States have deep roots in historical economic and political conditions related to racism and unequal access to resources and opportunities for better health spanning generations and across the life course. A recent assessment of the nation's progress toward meeting the ambitious goals of *Healthy People 2010* observed that "although some progress has been made, there is much work to be done toward the *Healthy People 2010* targets and both overarching goals" (Sondik et al., 2010). *Healthy People 2020* continues the focus on this area with the goal to achieve health equity and to eliminate

disparities. The National Healthcare Disparity Report, first produced in 2003 and published annually thereafter by the Agency for Healthcare Research and Quality (along with the National Healthcare Quality Report), found that even though coronary heart disease- (CHD-) and stroke-related mortality have decreased for all major racial/ethnic groups between 1980 and 2003, the burden of CVD and CVD risk factors remained disproportionately high in segments of the population defined by race, ethnicity, socioeconomic status (SES) and geography (AHRQ, 2006).

The selection and definition of population groups for study is critical to the process of building a framework for national surveillance of health disparities. Margaret Whitehead proposed a conceptual model of health equity and disparities in the early 1990s that offers a framework for examining the determinants of health disparities and provides a useful perspective to guide the development of a contemporary nationwide framework for CVD and COPD surveillance (Whitehead, 1991). Whitehead's seven determinants of health disparities are: (1) natural biological variation; (2) health-damaging behavior that is freely chosen; (3) the transient health advantage of one group over another when one group is first to adopt health-promoting behavior (as long as other groups have the means to catch up fairly soon); (4) health-damaging behavior in which the degree of choice of lifestyles is severely restricted; (5) exposure to unhealthy, stressful living and working conditions; (6) inadequate access to essential healthcare services and other basic services; and (7) natural selection or health-related social mobility involving the tendency for sick people to move down the social scale. Since Whitehead first outlined these seven determinants of health disparities in 1991, health-damaging behaviors such as smoking and unhealthy diet, which were presumed to be freely chosen, have also been linked to social networks that may strongly influence these behaviors (Christakis and Fowler, 2007, 2008). Therefore, such health behaviors must be considered within their social context, and they cannot be detached from the historical, sociocultural, and economic conditions that promote and constrain behavioral choices.

Surveillance of health disparities is complicated by the need to provide data from several distinct domains whose interaction leads to disparities in health and health care. The task is further challenged by the variability of determinants at the neighborhood, city, county, state, regional, and national levels, as well as between and among population groups and subgroups defined by race and ethnicity. For example, rather than beginning with race and ethnicity as the fundamental categories, health disparities could be tracked according to broad categories, such as social context and physical environment, age, and gender. The more proximate effects of other covariates (e.g., income, educational attainment, employment status and discrimination, health behaviors, the healthcare system, and psychosocial factors) could be assessed within a framework based on social context and physical environment, age, and gender. In this conceptual model (Figure 4-1), health indicators such as CVD and COPD prevalence and incidence, morbidity and mortality, obesity, hypertension, diabetes, and hyperlipidemia would be viewed as products of the interrelationship of the foregoing factors (Schulz et al., 2005).

EVIDENCE OF THE NEED FOR ONGOING SURVEILLANCE OF HEALTH DISPARITIES

Age and Gender

Age and gender are established categories for reporting health and healthcare surveillance data. Concomitant with the decline in death rates attributed to CHD in Americans over the past several decades, life expectancy has increased. Between 1980 and 2003, life expectancy increased by 4.8 years in American men and by 2.7 years in women.

CVD increases with advancing age in both women and men. Across the spectrum of CVD (hypertension, CHD, heart failure, valvular heart disease, peripheral arterial disease, and stroke), there are corresponding age-related increases in CVD morbidity and mortality (Yazdanyar and Newman, 2009). In 2007, the leading causes of death in women as well as men aged 65 and older were diseases of the heart. One in three women aged 65 and older has coronary artery disease, and the underlying disease process, atherosclerosis, begins at an early age in both sexes (NCHS, 2010).

In-hospital mortality related to acute myocardial infarction (AMI) is higher in women than in men, and the long-term prognosis after hospitalization for AMI has been shown to be worse in women than in men (Eastwood and Doering, 2005). Unadjusted mortality and complication rates remain higher in women than in men treated with percutaneous coronary interventions (PCIs). CVD risk scores also increase progressively with advancing age

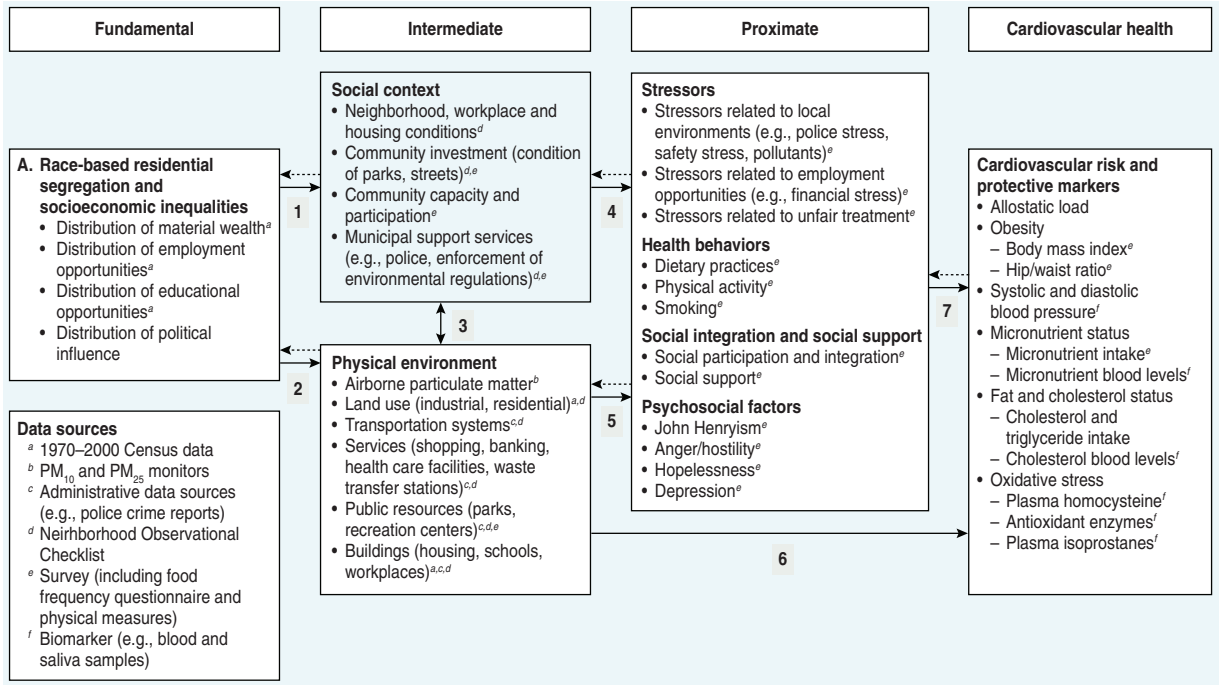

FIGURE 4-1 Conceptual model and data sources for Healthy Environments Partnership: Social and physical environmental factors and disparities in cardiovascular risk.
SOURCE: Schultz (2005).

in both men and women in the absence of diagnosed CVD. The prevalence of subclinical forms of CVD—such as carotid artery atherosclerosis and elevated coronary artery calcium score—have been shown to increase with advancing age (Rich and Mensah, 2009).

Performance of coronary revascularization soon after AMI in the elderly has become very common. Although the use of this effective treatment modality over time has increased considerably in men and women of all ages, age disparities continue (Pagé et al., 2010; Peterson et al., 2004). Because older patients with coronary artery disease often have additional comorbid illness, it is important to determine whether this procedure in older patients will translate into increases in quality of life and long-term survival in a cost-effective manner.

Similar to CVD, the occurrence of many chronic lung diseases increases with advancing age. An exception is asthma, which is more common in childhood (Brown et al., 2008; Mannino et al., 2002). In contrast to CVD, the occurrence of COPD has been increasing in recent decades, with the highest mortality rates observed among older white males (Brown et al., 2008; Lewis et al., 2009; Mannino et al., 2002). Although chronic lung diseases are more common among men, for selected conditions such as COPD the rate of increase has been greater among women. U.S. mortality rates from COPD, increased from 1980 through 2000, with a greater relative increase among females (20.1 to 56.7 per 100,000) compared with males (73 to 82.6 per 100,000). In 2000, the absolute number of deaths from COPD was higher among females compared with males. Between 2000 and 2005, mortality rates for females remained relatively flat, but declined among males (Brown et al., 2008). In addition to the relatively greater increase in mortality among females, women have a higher rate of use of inpatient services (Shaya et al., 2009). This may be partly explained by limited evidence suggesting that women are more susceptible to the adverse effects of cigarette smoke compared to men (Camp et al., 2009; Chatila et al., 2004; Dransfield and Bailey, 2006; Sin et al., 2007).

Race and Ethnicity

Because of the major roles race and (more recently) ethnicity have played in American political and social history, race and ethnic categorization of health and health care has been a distinguishing feature of health surveillance in the United States. As a result of segregation (racial, social, economic, and residential) throughout much of American history, race has served as a proxy for social, cultural, and economic features of populations and subpopulations described by race and ethnicity. The use of race as a social risk marker should be distinguished from the use of race as a biological risk factor. When used as a risk marker, race suggests a collinear association with some other quantifiable variable, such as income or education. By contrast, when used as a risk factor, race implies shared genetic heritage and consequent susceptibility to specific diseases such as sickle cell anemia or cystic fibrosis (Joseph et al., 2006; Osborne and Feit, 1992). When using race or ethnicity in health surveillance, it is important to acknowledge the social context in which these terms are used and to avoid presumptions of socioeconomic and cultural homogeneity or biological and genetic "sameness." Also important is recognizing that race and ethnicity are not biological or genetic variables that cause differences in health, but they are instead associated with other biological, social, or environmental risk factors that contribute to disparities in health between racial and ethnic groups (Ellison et al., 2007).

Understanding the root causes of health disparities requires surveillance at the population level for incidence and prevalence, predisposing factors, morbidity, mortality, and long-term outcomes. Other important factors are linkage of such data to environmental, residential, geographic, socioeconomic, cultural, and educational domains. Racial and ethnic disparities in CVD and COPD prevention, diagnosis, treatment, and outcomes have been extensively documented (IOM, 2003; Kaiser Family Foundation/American College of Cardiology Foundation, 2002). Prior surveillance data have shown that in comparison with white populations, racial and ethnic minorities generally have higher rates of CVD risk factors, CVD-related morbidity and mortality, poorer health, less adequate health care, and worse outcomes (Roger et al., 2010).

Although the overall occurrence of COPD is higher among non-Hispanic white males compared with other racial and ethnic groups, in recent years the occurrence has been increasing more rapidly among African Americans compared to whites (Brown et al., 2008; Coultas et al., 1994; Keppel et al., 2010; Kirkpatrick and Dransfield, 2009; Mannino et al., 2002). Moreover, relative disparities in mortality rates have increased from 1999 to 2006 for heart disease, from 1990 to 1998 for COPD, and from 1990 to 2006 for chronic lower respiratory disease (Keppel et al., 2010).

For COPD, limited evidence suggests that black men may be more susceptible to the adverse effects of cigarette smoke compared to white men (Chatila et al., 2004; Dransfield et al., 2006). Sarrazin and colleagues (2009) examined mortality rates among African American (n = 7,159) and white (n = 43,820) veterans admitted for a COPD exacerbation from 2003 to 2006. Overall mortality was lower among African Americans (7.1 percent) compared to whites (9.2 percent), with a risk-adjusted mortality ratio of 0.71. Although crude mortality rates from COPD have been higher among African Americans compared with whites, there may be no difference in these deaths after adjustment for age, body mass index, smoking, alcohol use, diabetes, hypertension, education, and sports index (Chamberlain et al., 2009). Among the heterogeneous Hispanic population, limited data are available about chronic lung diseases (Brehm et al., 2008). Mortality from CVD and COPD is lower among black and Hispanic immigrants compared to U.S.-born populations of the same race and ethnic groups, suggesting untoward effects of the American lifestyle (Singh and Hiatt, 2006). The influence of access to health care and quality of care among different racial and ethnic groups is discussed in greater detail in subsequent sections.

Measurement and classification of populations and subpopulations by race and ethnicity for surveillance has become more challenging because of increased immigration from Central and South America as well as Asia and Africa. Changes in the demographic characteristics of the U.S. population have also resulted from increased racial and ethnic admixture due to growth in the number of intermarriages and evolving conventions of racial and ethnic self-identification (Waters, 2000). The Pew Research Center reported that in 2008, a record one in seven of all new U.S. marriages were between individuals of a different race or ethnicity (with significant variation across U.S. regions). The Pew Research Center has produced estimates of future changes in the proportions of racial and ethnic groups. According to those estimates, from 2005 to 2050, the proportion of U.S. whites will decrease from 67 to 47 percent; the Hispanic population will increase from 14 percent of the population to 29 percent; U.S. blacks will remain at 13 percent of the population; and the proportion of Asians will rise from 5 to 9 percent (Passel and Cohen, 2008).

Nativity and Immigration

Growth in the proportion of foreign-born residents and their progeny in the United States has reinforced the importance of examining differences in the health and healthcare of immigrants, especially in regions, states, counties, or neighborhoods with significant proportions of immigrants. Because of their long history of discrimination, residential segregation, unemployment, and poor SES, immigrant populations can have less favorable risk factor awareness, diagnosis, treatment, and control. Immigrants and migrants have had a tendency to move to and live in areas populated by people with similar backgrounds. Residential segregation has held true historically, not only for immigrants but also for African American "migrants" already living in the United States and for many Native Americans. According to the 2000 Census, immigrants have settled most often in California, Florida, Illinois, New Jersey, New York, Pennsylvania, and Texas. Immigrants, particularly those who lack fluency in English, health literacy, and familiarity with the U.S. healthcare system, are at increased risk for some chronic diseases and injuries. Observed health disparities in specific racial and ethnic subgroups may result from shared social, economic, and physical environments as well as race or ethnicity.

The relationship between acculturation and chronic disease indicators is complex and may have a significant effect on observed health disparities. Surveillance systems typically have not focused on collecting and/or combining social, economic, and environmental data when addressing health disparities. Acculturation (or lack thereof) may influence the health of socioeconomically and culturally homogeneous populations, whether native born or foreign born, residing in the same neighborhoods. The effects of acculturation may be subgroup specific, with differing impacts on the burden of disease, risk factors, markers of comorbidities, and outcomes. In a study of participants in the Multi-Ethnic Study of Atherosclerosis, a higher prevalence of carotid plaque (a marker for carotid atherosclerosis) was observed among whites, blacks, and Hispanics who had been in the United States for more generations, as well as in whites with less education and blacks with lower incomes (Lutsey et al., 2008). Among immigrants from diverse ethnic backgrounds, longer length of residence in the United States has been associated with increased odds of obesity, hyperlipidemia, and cigarette smoking, even after adjusting for relevant confounding factors. High levels of acculturation have also been associated with poorer risk factor control or a higher prevalence of chronic disease risk factors. Immigrants who speak their native language at home or have resided briefly in the United States may have reduced risk factor control.

Assessing Hispanic ethnicity and disease or risk factor surveillance is complex because of differing geographic origins and admixture of various subgroups in the United States. The ancestry of Hispanics depends on the country of origin, the region of the country in which they first settle, and the region in which they ultimately reside. Hispanics in California emigrated predominately from Mexico, while Hispanics in New York emigrated largely from Puerto Rico and the Dominican Republic. Although both populations are "Hispanic," their ancestral origins differ considerably (Lai et al., 2009).

Furthermore, use of the term "black" to categorize persons of African origin may not be optimal in CVD and COPD surveillance. Approximately 6 percent of persons who self-identified as black or African American in the 2000 Census were not born in the United States (CDC, 2005). For example, in New York large subpopulations of people of African origin could be classified into different categories, such as Barbadian, Haitian, Jamaican, Nigerian, Panamanian, Senegalese, Trinidadian, or from other locations in the African Diaspora. The "black" category presents difficulties in surveillance because it encompasses a heterogeneous group, but does not account for variations within the group or among subgroups (Ford and Kelly, 2005).

Geography, Residence, and Environment

In Whitehead's formulation of health disparities, a distinction is made between damaging behaviors that are freely chosen (modifiable risk factors) and behaviors in which the degree of choice is severely restricted, such as birthplace and residence. Unhealthy living and working conditions and inadequate access to essential health services and other basic services (e.g., screening services) are influenced by environment, region, state, county, and neighborhood. Despite efforts to address health disparities by improving the quality of health care and health services delivered at the population, subpopulation, and individual levels, disparities in the major indicators of

high-quality health and health care persist, and differences in damaging or beneficial health behaviors have been shown to contribute to observed health disparities. These disparities persist in spite of the wide array of interventions available at the individual level, including improving primary and secondary prevention; increasing awareness, treatment, and control of predisposing factors; and increasing access to the latest diagnostic and therapeutic technologies. This persistence of health disparities has focused attention on other possible determinants of health disparities, including geography, residence, and environment (Do et al., 2008).

Substantial evidence shows geographic variation in risk factors, prevalence and incidence, morbidity, and mortality for CHD and stroke. For example, in a report of state-based prevalence estimates of CHD, variations among states by sex, race/ethnicity, and education were observed, with an approximate twofold difference between states with the highest and lowest prevalence rates of CHD (CDC, 2007). High heart disease mortality rates also have been observed in several U.S. regions, such as the "Coronary Valley" of the Ohio-Mississippi River Basin (Pickle and Gillum, 1999), and the "Heart Failure Belt" of the southeastern United States (Mujib et al., 2011).

The classic example of regional variation in CVD mortality is the "Stroke Belt." This belt is composed of 11 southeastern states where higher rates of stroke mortality have been observed compared to other U.S. regions (Lanska, 1993). The numerous hypotheses for the concentration of CVD and stroke mortality in the Southeast include geographic differences in the distribution of major cerebrovascular disease risk factors (e.g., high blood pressure, diabetes, cigarette smoking, and obesity) and differences in socioeconomic and environmental factors (Liao et al., 2009). However, even though many possible explanations for the Stroke Belt have been considered, the reasons for regional variation in stroke-related mortality have not been definitively established.

A possible explanation for the observed concentration of stroke mortality in the southeastern United States is the higher prevalence of hypertension among Southern-born blacks than in blacks born elsewhere. Geographic heterogeneity of hypertension suggests that differences in the prevalence of hypertension between blacks and whites are not constant, but they may vary depending on which geographic groups are compared. The presence of large variations in black–white differences suggests that race differences are not immutable (i.e., not simply genetic or biological) and may vary substantially by social and environmental context (Byers et al., 1998; Kershaw et al., 2010). Liao and colleagues (2009) observed that "socioeconomic status, hypertension, diabetes, coronary heart disease, and smoking are still the basic crucial contributors to the disparities. Most of these factors are either modifiable or potentially amenable to interventions. Given these findings, public health interventions are essential for progress in reducing the stroke burden in the Stroke Belt region."

Studies of increased stroke-related mortality in southeastern U.S. residents have generally suggested that stroke risk is primarily linked to residence in the Stroke Belt. Less is known, however, regarding the importance of birth versus residence in the Stroke Belt in native- and foreign-born blacks and whites. In a study of the association between birthplace and mortality from CVD among black and white residents of New York City, similar CVD death rates were observed for white and black men and white and black women born in the Northeast (Fang et al., 1996). Black men born in the South had death rates 30 percent higher than northeastern-born blacks and four times that of Caribbean-born blacks of the same sex and age. Higher rates of CVD mortality among blacks compared with whites may obscure substantial variation among blacks based on birthplace.

Disparities may be influenced by the characteristics of the local community or neighborhoods, which may engender healthy or unhealthy behavioral practices. The perception of neighborhood safety is positively associated with physical exercise, and this association is larger for minority groups than for whites. Neighborhoods also differ in the existence and quality of recreational facilities and open, green spaces. The availability and cost of healthful products in grocery stores also has been shown to vary across residential areas, and the availability of nutritious foods is positively associated with their consumption. In addition, it has been demonstrated that both the tobacco and alcohol industries heavily market their products to poor minority communities (Williams and Jackson, 2005). Furthermore, they are more likely to have jobs in workplaces that expose them to dusts, gases, and fumes, which have been associated with an increased risk for COPD, which disproportionately affects African Americans and Hispanics (Hnizdo et al., 2004).

Williams and Jackson (2005) observed the factors in Box 4-1 in the social environment that can initiate and sustain disparities in health.

BOX 4-1
Social Environment That Can Initiate and Sustain Disparities in Health

"***Socioeconomic status,*** whether measured by income, education, or occupation, is a strong predictor of variations in health . . . all of the indicators of SES [socioeconomic status] are strongly patterned by race, such that racial differences in SES contribute to racial difference in health. Moreover, the differences in health by SES within each racial group are often larger than the overall racial differences in health. ***Income*** also plays a role in understanding racial differences in CHD (coronary heart disease) mortality. For example, death rates from heart disease are two to three times higher among low-income blacks and whites than among their middle-income peers. In addition, for both males and females at every level of income, blacks have higher death rates from CHD than whites. Mortality from heart disease among low- and middle-income black women is 65 percent and 50 percent higher, respectively, than for comparable white women. . . . ***Health practices.*** Another pathway underlying the association between race and chronic diseases is the patterning of health practices by race and socioeconomic status. Dietary behavior, physical activity, tobacco use, and alcohol abuse are important risk factors for chronic diseases including CHD, stroke, and chronic lung disease. Moreover, changes in these health practices over time are patterned by social status. Disadvantaged racial groups and those with low SES are less likely to reduce high-risk behavior or to initiate new health-enhancing practices. . . . ***Stress.*** Exposure to psychosocial stressors may be another pathway linking SES and race to the development of poor health and adverse outcomes once disease has been diagnosed. The subjective experience of discrimination is a neglected stressor that can adversely affect the health of African Americans. Reports of discrimination are positively related to SES among blacks and may contribute to the elevated risk of disease that is sometimes observed among middle-class blacks. . . . ***Residential segregation.*** The persistence of racial differences in health after individual differences in SES are accounted for may reflect the role that residential segregation and neighborhood quality can play in racial disparities in health. Because of segregation, middle-class blacks live in poorer areas than whites of similar economic status, and poor whites live in much better neighborhoods than poor blacks. . . . ***Impact on income.*** Residential segregation is a central mechanism by which racial economic inequality has been created and reinforced in the United States. It is a key determinant of observed racial differences in SES because it determines access to education and employment opportunities. ***Violence.*** In addition, segregation creates health-damaging conditions in both the physical and social environments. Because of its restriction of educational and employment opportunities, residential segregation creates areas with high rates of concentrated poverty and small pools of employable and stably employed males."

SOURCE: Williams and Jackson, 2005.

Socioeconomic Factors

Traditionally, public health data have been stratified primarily by "race," for many years without the collection and reporting of socioeconomic data. With recent recognition of worsening economic and social inequalities, more attention has been focused on the contribution of socioeconomic factors to health disparities. Multiple socioeconomic factors contribute to health disparities, including income, education, residential segregation, stress, social and physical environment, employment, and many others. Disparities according to income and education have increased for smoking, with low-income persons smoking at higher rates. Diabetes prevalence has increased largely among persons from lower socioeconomic strata (Kanjilal et al., 2006).

Using data from NHANES III (1988–1994), Sharma and colleagues (2004) observed increased CVD risk factor clustering among Americans with low SES, particularly among non-Hispanic blacks. Among persons with high SES, Mexican Americans and non-Hispanic blacks have a higher risk of CVD than non-Hispanic whites. Low educational attainment may also impact mortality rates. In a study examining the relationship of education and race to mortality, Jemal and colleagues (2008) found that "48 [percent] of all deaths among men aged 25–64

(white, black, and Hispanic) and 38 [percent] of all deaths in women would not have occurred in this age range if all segments of the population experienced the death rates of college graduates. However, the total number of deaths associated with low education status was not confined to any single racial or ethnic group."

Using NHANES data from 2001–2006, Karlamangla and associates (2010) evaluated the association between SES and ethnic disparities in cardiovascular risk. They observed marked inverse socioeconomic gradients with risk in all race/ethnicity groups, except foreign-born Mexican American men. Disparities according to race/ethnicity were seen in some, but not all, socioeconomic strata, with some non-Hispanic blacks and U.S.-born Mexican Americans having higher risk, and some foreign-born Mexican Americans having lower risk.

Low SES is associated with a higher prevalence of risk factors, greater chronic disease burden, and higher expenses for health care, medications, and hospitalization. The sick and poor are at risk of moving even farther down the socioeconomic ladder (Fiscella and Williams, 2004). The reverse is also evident: those at the highest socioeconomic rank are likely to be more educated, have better risk factor profiles, improved health, and better health-related outcomes. With greater access to information, more financial resources, greater access to high-quality health care, and the capacity and capability to benefit from advances in pharmaceuticals and healthcare technology, those who are more advantaged can move further up the socioeconomic ladder, while disadvantaged populations remain mired in unhealthy neighborhoods with the highest burden of CVD and COPD. Improving the national surveillance of SES and its relationship to indicators of risk and health outcomes is a critical step toward reducing health disparities.

PRIORITIES FOR SURVEILLANCE OF HEALTHCARE DISPARITIES

Primary Prevention

Reducing the magnitude of clinically evident CVD and COPD in populations that bear a disproportionate burden of disease is an essential element in the struggle to eliminate health disparities. The principal goals of primary prevention include risk assessment; reduction of risk by control of key pre-disposing factors, including cigarette smoking, elevated cholesterol, elevated blood pressure, obesity, and diabetes; and limitation of progression of subclinical disease.

The prevalence of hypertension in U.S. blacks is among the highest in the world (Roger et al., 2010). Pre-hypertension (blood pressure levels greater than 120/80mmHG, but less than 140/90) is more prevalent in men than women, and more prevalent in African American men aged 20–39 years than comparably aged whites and Mexican Americans. As in other subclinical CVD conditions, primary prevention for individuals with pre-hypertension is recommended through vigorous lifestyle and diet modification, and may also include affordable pharmacologic therapy if shown to improve health outcomes (Greenlund et al., 2004; Pimenta and Oparil, 2010).

Secondary Prevention

Successful therapeutic interventions in patients with CVD—particularly myocardial infarction and stroke—have expanded the population of U.S. individuals who could benefit from the enhanced use of evidence-based secondary interventions. Interventions for secondary prevention include lifestyle modifications and pharmacologic treatments to control smoking, hypertension, hyperlipidemia, and diabetes, as well as coronary revascularization procedures that can relieve symptoms and, in some cases, extend survival. The growing number of older adults with CVD and COPD requires specific surveillance of health disparities, with special attention to monitoring adherence to healthy lifestyle practices and effective treatment regimens and the effect of different treatment approaches on quality of life, recurrence, and long-term prognosis. Standardized surveillance approaches for monitoring the effectiveness of secondary prevention are needed (Willson et al., 2010).

Coronary revascularization procedures such as coronary artery bypass (CABG) and PCI, along with bare-metal and drug-eluting stents, have advanced the management of CHD. Racial and ethnic differences in the receipt of catheterization and coronary revascularization were reported in early studies (Gillum et al., 1997; Kressin and Petersen, 2001); however, more recent investigations suggest a reduction in racial disparities in the use of these

interventions. Brown and colleagues (2008) analyzed the receipt of cardiac catheterization, PCI, and CABG by age, sex, insurance status, and race among black and white patients discharged from U.S. hospitals over a 25-year period beginning in 1979. They found that consistent and significant disparities in the receipt of cardiac catheterization, PCI, and CABG by age, sex, insurance status, and race persisted across the 25 years of study; however, attenuation of these differences were observed from 1979 to 2004 for each subgroup examined. Specifically, although blacks were 27 percent less likely to receive diagnostic cardiac catheterization in 1979, they were only 11 percent less likely to undergo cardiac catheterization in 2004 (Brown et al., 2008). Racial disparities in the use of drug-eluting stents have also been reported (Gaglia et al., 2009; Hannan et al., 2007).

A number of investigations have been conducted in different patient populations to explore potential racial differences in healthcare use and quality of care for persons with COPD. In a Medicaid population of 9,131 patients with COPD and asthma, African Americans had lower overall healthcare use and costs when compared to whites, including physician office visits and outpatient and inpatient services (Shaya et al., 2009). Gordon and coworkers (2002) examined the quality of processes of care for CHF and COPD at Veterans Administration hospitals and found no difference in the quality of care provided to blacks and whites. Tsai and colleagues (2009) examined racial and ethnic differences in processes and outcomes of emergency room care among a cohort of 330 patients with COPD enrolled from 24 emergency departments from 15 states. Compared to whites, African American and Hispanic patients had lower SES and primary care access and more frequent exacerbations, but there were no statistically significant differences in the processes or outcomes of care. Hasnain-Wynia and coworkers (2010) found that a higher proportion of racial and ethnic minorities were cared for at lower performing hospitals. Among patients with severe COPD waiting for lung transplantation, African American patients were less likely to have a transplant and more likely to die (Lederer et al., 2008).

Rates and trends of risk-adjusted hospitalization rates for specific conditions provide population-level evidence on the adequacy of access to primary care, known as ambulatory care sensitive conditions (ACSCs), and effectiveness of various interventions (AHRQ, 2004). The cardiovascular and chronic lung diseases considered to be ACSCs include angina, hypertension, congestive heart failure (CHF), asthma, and COPD (AHRQ, 2004). Variations in risk-adjusted hospitalization rates for ACSCs have been examined to determine racial, ethnic, socioeconomic, and geographic disparities for these conditions (Bindman et al., 2008; Jackson et al., 2011; Laditka and Laditka, 2006; O'Neil et al., 2010). A nationwide sample of community hospital discharge data demonstrated that compared to non-Hispanic whites, African American men (adjusted relative rates of 1.9 and 1.6 for ages 19–64 years and 65+ years, respectively) and Hispanic males (2.6 and 2.3, respectively) and females (1.6 and 2.1, respectively) had higher rates of hospitalizations for COPD, adjusted for disease prevalence (Laditka and Laditka, 2006). On the other hand, an analysis of admission rates in North Carolina among Medicare beneficiaries for ambulatory sensitive conditions, including COPD, found that African Americans had lower admission rates for COPD compared to whites (odds ratio 0.67) (Howard et al., 2007). In Texas, wide variations have been found for hospitalization rates for COPD. The highest rates of hospitalization have been found among rural counties, the elderly, non-Hispanic whites, and women in urban areas (Jackson et al., 2011). African Americans had lower hospitalization rates compared to non-Hispanic whites, and Hispanics had the lowest rates.

CONCLUSION

Untangling the effects of environment, income, education, race, ethnicity, and genetics may lead to the more precise targeting of preventive, diagnostic, and therapeutic interventions. This in turn will contribute to the elimination of health disparities, reduction in the magnitude of chronic disease, and improvements in prognosis and quality of life in those with established disease. However, there is a lack of standardization in the collection of race, ethnicity, and language data at the federal, state, and local levels. This lack of standardization creates difficulty in identifying disparities and appropriately targeting quality improvement efforts. Surveys such as the BRFSS, NHANES, and NHIS routinely collect self-reported multiple race data on individuals, and collect ethnicity data independent of race. However, gaps in the collection of disparity data are evident at various levels. For example, among the sources of data collected by Centers for Medicare & Medicaid Services, only the Consumer Assessment of Health Plans Survey allows multiple race designation of individuals, and only the Medicare Current Beneficiary

Survey, the Consumer Assessment of Health Plans Survey, and the Medicare End Stage Renal Disease Program collect ethnicity data that are independent of race. Methodological issues concerning the use of data to assess racial and ethnic disparities include the validity of the classification of individuals' race and ethnicity, sample size limitations, the smallest analyzable geographic or institutional unit, and the availability of data on other cultural or socioeconomic characteristics (Sequist and Schneider, 2006).

The principal challenge is to develop systems that more effectively and efficiently link conventional surveillance data to more contextually relevant data (e.g., SES, birthplace, acculturation, geography, language, and insurance). A wide array of factors may interact to determine population health, including biological or genetic factors, health behaviors and lifestyle practices, socioeconomic status, the environment, access to health services, and cultural or linguistic isolation. Appreciation of the heterogeneity of the general population and the many health-related factors that distinguish populations, subpopulations, and groups within subpopulations from each other has grown over time and in importance. Therefore, a critical need remains for standard definitions of CVD and COPD data elements, as well as a need for consensus regarding the operationalization of race and ethnicity, SES, and biological risk factors in the surveillance of CVD and chronic lung disease.

Impressive gains have been achieved in life expectancy for the overall American population, as well as distinct subpopulations defined by race and ethnicity. However, inequities in health status and health systems remain in many neighborhoods, cities, states, and regions. A contemporary and ongoing national framework for the surveillance of CVD and COPD disparities will facilitate the development of actionable policies and programs informed by data gathered at the national, regional, state, and community levels.

For example, at the national and state levels, incidence and prevalence information accompanied by improved data on race/ethnicity and geographic region will enable more effective goal setting for national and state programs and policies aimed at eliminating health disparities. This aggregation and reporting can provide information about where persistent disparities in health and health care exist. Local-level data on health behaviors coupled with local-area data on race/ethnicity, language, nativity, and immigration can aid health plan managers in developing culturally and linguistically appropriate interventions to modify unhealthy behaviors. These data will help providers understand the populations they serve, address disparities, and improve and monitor healthcare quality. A lack of valid race and ethnicity data creates difficulty in identifying disparities and appropriately targeting strategies to address them.

This framework will support efforts to advance the prevention and effective treatment of chronic disease to ensure the highest quality health care for the U.S. population as a whole and for important subgroups in this population. The committee concluded that the national framework for surveillance would be enhanced by the recommendations of the Institute of Medicine, *Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement* (2009). Therefore the committee supports these recommendations.

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5

Existing Surveillance Data Sources and Systems

INTRODUCTION

The Centers for Disease Control and Prevention (CDC) defines public health surveillance as "ongoing, systematic collection, analysis, interpretation, and dissemination of data regarding a health-related event for use in public health action to reduce morbidity and mortality and to improve health" (CDC, 2001). This definition is particularly appropriate for acute health issues, such as infectious diseases and injuries, in which an exposure, a diagnosis, or an event is a data point for tracking incidence. Surveillance approaches vary in terms of scope, methods, and objectives: some are established to track particular diseases such as specific cancer types or communicable infections; others track behaviors, health conditions, or events such as smoking, obesity or childhood window falls, or occupational hazards such as on-site injuries.

Surveillance data can be used to estimate the magnitude of specific problems, determine the distribution of illness, portray the natural history of a disease, generate hypotheses, stimulate research, evaluate control measures, monitor changes, and facilitate planning. Data sources and methods for surveillance systems include notifiable diseases, laboratory specimens, vital records, sentinel surveillance, registries, surveys, and administrative data systems.

Surveillance can be either passive or active. With passive surveillance, reports are received from physicians, hospitals, laboratories, or other individuals or institutions. Examples of passive surveillance systems include the Food and Drug Administration's (FDA's) Adverse Events Reporting System (AERS), which is focused on patient safety, and the Vaccine Adverse Events Reporting System (VAERS), which is operated by the CDC in conjunction with the FDA and is concerned with the negative effects of licensed vaccines. Passive surveillance is a relatively inexpensive strategy, but its reliance on people and institutions to initiate providing data reduces completeness and data quality. Active surveillance approaches regularly contact reporting sources to obtain information. It is generally considered more complete, but such a system is more costly than a passive system (Groseclose et al., 2000).

While there is no single nationwide surveillance system for cardiovascular and chronic lung diseases, a number of surveys, registries, cohort studies, and vital statistics are used by different stakeholders to gather different kinds of information about these diseases. To fulfill its task to develop a nationwide framework for surveillance, the committee sent 49 requests for information to different institutions engaged in some form of relevant data collection.[1] Each request asked for information about the main purpose of the data collection effort; sample characteristics; data collection methods, sources, and frequency; the kind of information obtained (i.e., incidence,

[1] While every attempt was made to include as many systems as possible, systems about which the committee was unaware are likely to exist.

prevalence, risk factors, functional health outcomes, clinical care information, and demographic characteristics); costs and source(s) of funding for the system; and data dissemination (i.e., online availability of data, online query, and who can obtain access).

Of the 49 requests, 35 responses were received. Information on eight additional data collection approaches was obtained through published literature and online queries (see Appendix A). The following discussion reviews the strengths and limitations of various types of data collection efforts, including surveys, registries, cohort studies, administrative and health services data, vital statistics, and data regarding hospital performance.

DATA COLLECTION EFFORTS

Surveys

Routine surveys are particularly valuable surveillance tools for chronic diseases and health-related behaviors. In general, surveys are most useful for disease surveillance when they ask people about information for which they may be the most valid and reliable source (e.g., their own private behaviors, attitudes, or mental health status), or for which they can report with reasonable reliability, even if they are not the only or most valid source of information (e.g., whether he or she went to the doctor in the past month). In some cases, surveys link such self-reported data to data collected from other sources. The following sections of this chapter discuss major surveys at the national level as well as examples of state and local surveys. The discussion includes a description of the purpose of the survey, its methods, the extent to which data are collected on topics relevant to cardiovascular and chronic pulmonary diseases, and how data are disseminated. Each description includes a brief discussion of strengths and limitations.

National Population-Based Surveys

The Behavioral Risk Factors Surveillance System (BRFSS) The BRFSS, nationally coordinated by the CDC and conducted by state health departments in all 50 states and the District of Columbia, is a state-based system of cross-sectional health surveys of adults. It collects information on health risk behaviors, preventive health practices, and healthcare access, primarily related to the areas of chronic disease and injuries. The BRFSS has been the primary source of state-level population health estimates from surveys and has been available in all states since 1984. States may request information from the CDC; the information includes samples of telephone numbers with substate or local strata, an option taken by 41 states. The core questionnaire is required of all states. Data collection is funded by several sources, including state and federal agencies and private organizations. The CDC supports a portion of the data collection efforts, and the states provide their own funding for optional modules and state-added questions. Private partners also support collection of data in the different states. BRFSS data are widely used for policy development and advocacy at both the national and state levels.

The BRFSS questionnaire is administered on a continuous basis by telephone using random-digit dial sampling methods. The design consists of a probability sample of all households with telephones in the state. Survey respondents are between the ages of 18 and 99, and only one adult per household is interviewed. As part of the core survey questionnaire developed by the CDC, self-reported information is routinely collected on diagnosed health conditions, including stroke, congestive heart failure (CHF), coronary heart disease (CHD), diabetes, and asthma, but not chronic obstructive pulmonary disease (COPD). The CDC provides an optional module on COPD that states may include at their discretion (and expense). The core questionnaire also collects information on diagnosis of cardiovascular risk factors, including hypertension, diabetes, and high cholesterol. Questions on tobacco use, alcohol consumption, physical activity, nutrition, and weight status, including consumption of fruits and vegetables, are also asked. Limited data are also collected on access to, and use of, healthcare services, including preventive services.

Sociodemographic data collected include age, sex, race/ethnicity, marital status, education, employment, and household income. Most states and localities with BRFSS surveys have the ability to examine prevalence of health conditions and risk factors by major race/ethnic and income groups. Race/ethnicity is collected as Hispanic, white, black or African American, Asian, Native Hawaiian or Other Pacific Islander, and American Indian or Alaskan

Native. Only some states collect explicit data on nativity. Geographically, in addition to state-level estimates, the CDC currently aggregates BRFSS data to produce a limited set of annual estimates for 177 metropolitan and micropolitan statistical areas and 166 counties (which vary from year to year due to sampling variations).

The BRFSS provides annual findings and data files via the website http://www.cdc.gov/brfss/ and on CD-ROM, with additional information on survey instruments, other documentation materials, sets of trend analysis tables for the states and the nation, and sets of demographic-specific tables for estimates of risks and conditions, including bar charts for comparison of areas or survey years. Results are also easily accessible via interactive tools, although the "Web Enabled Analysis Tool" is available for limited survey years. At the time this report was in press, data were available from 1984 through 2009. More than 1,500 peer-reviewed journal articles have been published using BRFSS data.

Strengths and limitations The BRFSS has numerous strengths for use in surveillance. The CDC's strong control over survey questions to be used ensures that data collected by each state's BRFSS are reasonably comparable to data collected by other states. As an ongoing survey, it enables tracking of trends. The BRFSS collects information on prevalence of self-reported asthma/adult asthma history, cardiovascular disease (heart attack/stroke), diabetes, and health risk factors that include cholesterol and hypertension awareness (CDC, 2009b). It is adaptable for local use at the expense of each jurisdiction that wishes to use it.

The prevention of CVD and chronic lung disease is a long-term effort that must address risk factors throughout the life course, and the absence of significant information collected about children and adolescents means that the BRFSS does not provide local surveillance of obesity, diet, and physical activity in these age groups. Although other surveys do collect such information on children and adolescents, not being able to link that information to parents' information is a handicap for prevention efforts. In addition, the BRFSS's thin measurement of health insurance coverage and access to care limits its value for assessing factors that affect the receipt of clinical preventive and disease monitoring services.

Because it typically does not collect locally representative survey samples, the BRFSS has limited use for local-level analyses and research. Such research is necessary to support efforts to address geographic and social disparities. The CDC recognized the need for local data and used aggregated BRFSS data to produce a limited set of annual estimates for local geographic areas, but these vary from year to year due to sampling variations. It is doubtful that these can meet needs for in-depth data for research and analysis of local variations in chronic diseases and their risk factors. Nearly a third of states have expanded state BRFSS samples at their own expense to generate representative data sets for local substate strata. Such efforts are described in the section below on state surveys.

The BRFSS also relies on self-reported information. It does not collect blood specimens or contain information on incidence of disease and health outcomes or data on chronic bronchitis or emphysema (IOM, 2009). The required core and optional module BRFSS questionnaires of the survey examine disease history and signs and symptoms of disease (e.g., shortness of breath), but the BRFSS core does not collect national data about chronic lung disease, with the exception of asthma. Furthermore, response rates to the BRFSS are lower than ideal and declining, a limitation that it shares with all telephone surveys, and as a telephone survey, it does not include people without telephones.

Youth Risk Behavior Surveillance System (YRBSS) The YRBSS is focused on monitoring priority health risk behavior, including physical inactivity, dietary behaviors, the prevalence of obesity, and asthma among students in grades 9–12 (CDC: http://www.cdc.gov/HealthyYouth/yrbs/index.htm). The survey is conducted by the CDC and by state, territorial, and local education and health agencies and tribal governments. The purpose of this survey is to provide critical behavioral information on adolescents nationwide. At the state level, information is used for school- and community-based program evaluation and policy development as well as for national research and surveillance of health behavior and health risk disparities.

Data are collected every other year, usually during the spring semester. Information is collected from a nationally representative sample of public and private high school students (grades 9–12) in each participating jurisdiction as well as a representative sample of students enrolled in middle schools and alternative schools. The survey is administered in 10 to 15 sites per cycle. A class is randomly selected to participate, and all students in that class are asked to take part in the survey. The survey is a self-administered written questionnaire conducted in school classrooms.

The YRBSS monitors six categories of priority health risk behaviors among youth and young adults, three of which pertain to CVD risk factors. These include behaviors that contribute to unintentional injuries and violence; sexual behaviors that contribute to unintended pregnancy and sexually transmitted diseases, including HIV infection; tobacco use; alcohol and other drug use; unhealthy dietary behaviors; and physical inactivity. In addition, the YRBSS monitors the prevalence of obesity, diagnosed asthma, and prevalence of asthma attacks.

Black and Hispanic students are oversampled in the YRBSS to examine race- and ethnic-specific estimates, but the 2009 sample size from other racial and ethnic groups is "too small to permit meaningful analysis" at the national level (http://www.cdc.gov/HealthyYouth/yrbs/pdf/press_release_yrbs.pdf). However, some states and localities have sufficiently diverse samples to examine other race and ethnic subgroups. No information is collected regarding household or neighborhood income or nativity.

Similar to the BRFSS, the CDC provides annual findings and data files via the website www.cdc.gov/yrbs,[2] with additional information on survey instruments and other documentation materials. Results are also easily accessible to non-researchers via interactive tools and summary tables that can be queried.

Strengths and limitations The YRBSS shares many of the same strengths as the BRFSS for surveillance, despite the different methodologic design. Like the BRFSS, the CDC's control over core survey questions to be used in the YRBSS ensures that data collected by each state are comparable to data collected by other states, and results are summarized in an annual *Morbidity and Mortality Weekly Report* (MMWR). As an ongoing cross-sectional survey, it enables tracking of trends in prevalence. Unlike the BRFSS, the reported response rate of YRBSS surveys is typically 70 percent or greater. Finally, the CDC allows states and localities to add a small subset of questions of local import, thus making it somewhat flexible for local adaptation. The information collected enables surveillance of the prevalence of self-reported asthma and health risk factors (CDC, 2010).

Although the YRBSS has several strengths, its main shortcomings include its limited representativeness and lack of detailed questions on risk factors for CVD and other chronic diseases. In most states and localities, the YRBSS is conducted using sampling frames of public high schools only, and thus it is not generalizable to private, parochial, or some vocational high school students, nor does it include adolescents who have dropped out of high school. In terms of risk factors, the survey does not collect detailed information on factors such as family medical history, food consumption or physical activity patterns, or access to clinical and preventive services. In addition, the lack of information on household or neighborhood socioeconomic status, nativity, or ancestry limits the ability to examine disparities in risk factors. The YRBSS does not collect information that could link adolescents' responses to information on adults, precluding analyses of risk factors within families and households. Because it does not collect locally representative survey samples, the YRBSS has limited use for local-level analyses and research. Finally, like the BRFSS, the YRBSS relies on self-reported information and does not collect blood specimens nor does it contain information on incidence of disease and health outcomes, chronic bronchitis, or emphysema (IOM, 2009).

National Health Interview Survey (NHIS) The NHIS has monitored the health of the nation since 1957. It is a federally funded survey conducted by the National Center for Health Statistics, which provides data that are used widely to monitor trends in illness and disability, to progress toward achieving national health objectives, for determining barriers to accessing and using appropriate health care, and for evaluating federal health programs. The data also are used for public health research and policy development nationwide and regionally.

The NHIS is a cross-sectional household interview survey of men and women between the ages of 1 and 99. It is conducted in English and Spanish by interviewers employed and trained by the U.S. Census Bureau. The sampling plan follows a multistage area probability design that permits the representative sampling of households and non-institutional group quarters (e.g., college dormitories), and the plan is redesigned after every decennial census. All states and the District of Columbia are included in the sample. Sampling takes into account multiple geographic levels (e.g., local, state, national), but the sampling design is primarily aimed at making national and regional estimates.

For the Family Core component, all adult members of the household aged 17 and older who are at home at the time of the interview are invited to participate and to respond for themselves. Information about children and adults not at home during the interview can be provided by a responsible adult family member who is 18 or older

[2] ICF Macro is a research and technology consulting firm.

and who resides in the household. For the Sample Adult questionnaire, one civilian adult per family is randomly selected and responds for her- or himself. Data are collected annually and continuously, with a different, large cross-sectional sample of approximately 35,000 households each year, with a response rate of nearly 90 percent of eligible households (http://www.cdc.gov/nchs/nhis/about_nhis.htm).

The NHIS questionnaire uses a computer-assisted personal interviewing (CAPI) model. The revised NHIS questionnaire, implemented since 1997, has core questions and supplements. The core contains four major components: Household, Family, Sample Adult, and Sample Child. The household component collects limited demographic information on all of the individuals living in a particular house. The family component verifies and collects additional demographic information on each member from each family in the house and collects data on topics such as health status and limitations, injuries, healthcare access and use, health insurance, and income and assets. The supplements are used to respond to new public health data needs as they arise, particularly those for which other federal agencies provide funding. The most recently published NHIS core questionnaire includes 5 questions on diabetes, 13 questions about CHD and stroke, 5 on asthma, 1 on emphysema, and 1 on bronchitis.

The current NHIS sample design oversamples blacks, Hispanics, and Asians and persons over age 65. National and regional prevalence estimates on conditions in these race/ethnicity and age groups, as well as by household income group and nativity, are robust.

Data files are released to the public through the NHIS website. The results of different studies using NHIS data are published in several types of reports released through the Internet or in journal articles. Information is also available at http://www.cdc.gov/nchs/nhis.htm.

Strengths and limitations The NHIS serves as the nation's benchmark health survey. The main strengths of the NHIS are its representativeness, large sample size, adequate sampling of minorities, good response rates, and data on CVD and chronic lung conditions and risk factors. Incidence of self-reported diabetes and CVD can also be roughly estimated, and it is possible to link the survey to national mortality statistics.

The major limitations of NHIS are the lack of physical examinations or directly measured risk factors and disease, and the inability to generate local estimates. Larger states (now approximately 20) have sufficient sample sizes so that reliable state estimates can be made, although that is not the case for the remaining states.

National Health and Nutrition Examination Survey (NHANES) A federally funded survey, also conducted since the early 1960s[3] by the National Center for Health Statistics, NHANES is the largest and longest running national source of objectively measured health and nutrition data. Data are collected on a broad range of health topics through personal household interviews, physical examinations, and laboratory testing. NHANES data provide objective assessments of prevalence of major chronic and infectious diseases nationally, and they generate key indicators of disease management for benchmarking purposes. They are used for surveillance and policy development by a range of federal agencies, and in etiologic research by a wide range of government, academic, and other institutions. Historically, NHANES was conducted periodically, but starting in 1999, NHANES has been in the field continuously. NHANES is designed to assess the health and nutritional status of a statistically representative sample of the civilian, noninstitutionalized population of the continental United States. NHANES conducts a cross-sectional, household-based survey of nearly 10,000 adults and children aged 2 months and older. The sampling plan follows a multistage area probability design that permits the representative sampling of households. Health measurements are performed in specially designed and equipped mobile centers, which travel to locations nationwide. The study team consists of a physician, medical and health technicians, and dietary and health interviewers. Many of the study staff are bilingual in English and Spanish. A series of computer-assisted questionnaires are administered in both the home and in a mobile examination center, followed by a physical examination, and finally, biological specimens are collected as part of a laboratory component.

Detailed information on chronic conditions—including cardiovascular disease, diabetes, and respiratory health and disease—are collected by questionnaire, and participants undergo comprehensive dietary interviews and body measurements. The physical examination includes several measures relevant to CVD and respiratory diseases, including blood pressure and spirometry, as well as cardiovascular fitness, body mass index, and body

[3] NHANES evolved from the Health Examination Survey, which was launched in 1959 (IOM, 1996).

composition. Relevant biomarkers include cholesterol and triglyceride measures, C-reactive protein, and fasting plasma glucose. NHANES uses collected data to produce estimates of medically defined prevalence of CVD and its clinical risk factors, diabetes, and lung diseases (asthma, chronic bronchitis, emphysema) in the United States.

The current NHANES sample design oversamples blacks and Hispanics, and a new feature of the current sample design is that Asian persons are also oversampled. Detailed information is also collected on household income, nativity, education, and occupation, allowing for fairly sophisticated analysis of health disparities.

The continuous NHANES survey data are released on public-use data files in 2-year increments**.** Information about NHANES, downloadable public-use data sets, and published reports are made available through the Internet (http://www.cdc.gov/nchs/nhanes.htm) and on easy-to-use CD-ROMs. More than 10,000 peer-reviewed journal articles have been published using NHANES data; a bibliography is available on the survey homepage.

Strengths and limitations NHANES is also a benchmark national health survey. It is one of the few population-based surveys that include validated examination measures, biological specimen collection, and limited measures of health status. Rigorous training in recruitment and data collection ensures high response rates, national representativeness, and high-quality data collection. The sample size is large enough for fairly precise prevalence measures at the national level. The national serologic repository allows for trend estimation of newly emerging biomarkers, such as C-reactive protein.

Since the inception of the continuous NHANES, any 2-year analysis may be limited in sample size, and statistical power consideration should be used to determine if sample size is sufficient for a particular analysis or if additional years of the survey need to be combined to produce statistically reliable analysis. Interview (questionnaire) data are based on self-reports and are therefore subject to recall problems, misunderstanding of the question, and a variety of other factors. Despite high standards for data collection, examination data and laboratory data are also subject to measurement variation and possible examiner effects. The survey does not collect data on incidence of acute CVD events or exacerbations of chronic lung disease. Finally, the cohort is not large enough to generate state or local prevalence estimates.

State Surveys

Nearly a dozen states have established separate surveys to meet their needs for local and state population health data. The growth of state and local health surveys is a positive development, demonstrating that policy makers at those levels recognize and are responding to the need for population health data. Although these surveys differ in the topics covered, measures used, and sample designs, many adopt designs and questions from the national surveys described above, and they have considerable use for tracking change and disparities in CVD and chronic lung disease within their target geographic areas. Their value for a national surveillance system is limited in measuring differences across geographic domains for which consistency of measurement is critical (Gold et al., 2008). A small number of states are experimenting with health examination surveys modeled after NHANES, including the Survey of the Health of Wisconsin (SHOW) (http://www.show.wisc.edu/) and the Arkansas Cardiovascular Health Survey (http://www.healthy.arkansas.gov/programsServices/chronicDisease/Initiatives/Documents/ARCHES/ARCHESQuestionnaire.pdf). The committee selected three examples of ongoing state telephone surveys to illustrate these developments.

California Health Interview Survey (CHIS) One of the nation's largest ongoing health surveys, the CHIS is the state's primary source of data for public health surveillance and tracking of changes in health insurance coverage as well as eligibility for public healthcare coverage programs. The CHIS covers a broad range of health issues, including health conditions and behaviors, mental health, health insurance, healthcare use and access, and special modules on the health of women, children, and persons over age 65. CHIS data are used for policy development and advocacy within California at both the state and county levels. They are also used for national research and surveillance of racial, ethnic, and other social disparities in health and health care. The CHIS is funded by multiple public agencies and private organizations at the federal, state, and local levels.

Over any 2-year period, the CHIS conducts telephone interviews with about 50,000 households, selected by random-digit dialing (RDD), throughout the state. CHIS develops samples for each of 44 geographic strata,

including 41 single-county strata and 3 multiple-county strata; two large counties also include several subcounty strata. Data files include samples for each geographic stratum. Households are selected for participation through random-digit dialing sampling of landline phones and cell phones. In each household, one adult (aged 18 or over) is randomly sampled for interview. In addition, in households with children, one child (through age 11) is randomly sampled and the most knowledgeable parent is interviewed, and one adolescent (aged 12–17) is sampled and directly interviewed (after obtaining parental permission).

The CHIS collects information on asthma (diagnosis, asthma symptoms, emergency room visits, and control and management of asthma), diabetes (pre-diabetes or borderline diabetes, diagnosis, and management of diabetes), and heart disease (heart attacks, heart failures, congestive heart failure, and control and management). Information is also collected on conditions and behaviors associated with these diseases, such as diet, physical activity, and smoking. Information is collected on access to and use of health care, including health insurance coverage, usual source of care, doctor visits, delays in getting care, medical home, communication problems with doctor, and long-term care. CHIS questions are typically drawn or adapted from the NHIS, BRFSS, and other national surveys.

The survey also collects detailed sociodemographic information, including age, sex, detailed race/ethnicity, marital status, education, employment, household income, veteran status, sexual orientation, citizenship and immigration status, languages spoken at home, and English-language proficiency. Questionnaires are translated and administered in English, Spanish, Mandarin, Cantonese, Korean, and Vietnamese. The sample is designed to collect adequate samples of key racial/ethnic populations and to reflect the geographic and other social diversity of California.

The CHIS is conducted by the University of California–Los Angeles (UCLA) Center for Health Policy Research in collaboration with several government agencies and private foundations that fund it. The center uses multiple approaches to disseminate CHIS data and findings. *Ask*CHIS, a free easy-to-use online data query tool, enables users to tailor detailed descriptive analyses for any CHIS health topic by detailed demographics and geographic locations (http://www.chis.ucla.edu). Public-use data files for all years can be downloaded from the CHIS website in SAS, SPSS, and Stata data formats. Confidential CHIS data can be accessed by researchers through the secure CHIS Data Access Center (DAC). Nearly 200 peer-reviewed journal articles have been published using CHIS data. Workshops on data access and use are conducted for community organizations and agencies and for researchers. Further information about the survey is available at http://www.chis.ucla.edu.

Ohio Family Health Survey (OFHS) This survey, conducted in 1998, 2004, 2008, and 2009, provides state policy makers with information about the health status, healthcare use, health insurance coverage, and healthcare access of Ohioans at the state and county levels. Special attention is paid to those on Medicaid and the uninsured. OFHS data are used for health policy development within Ohio, and by local jurisdictions in their health planning and policy development. This survey is supported by various government and health agencies in Ohio.

OFHS interviews about 50,000 adults, aged 18 years or older, by telephone and obtains proxy responses for more than 13,000 children, one from each household. Households are randomly selected by RDD to landlines and cell phones. The sample includes 88 county strata and random selection of an adult respondent within each household. Questionnaires are translated and administered in English and Spanish.

The questionnaires include three questions related to heart conditions (heart attacks, coronary heart disease, strokes, and congestive heart failure), three questions on asthma, and five questions on diabetes. Information is obtained about three risk factors: smoking, weight, and height. Additional information is collected on health insurance coverage, coverage for supplemental services (vision, dental, prescriptions, mental health care), healthcare use, access to care, and unmet needs for care. OFHS questions are typically drawn or adapted from the NHIS, BRFSS, and other national surveys.

The survey collects information about demographics (marital status, gender, and education), employment characteristics, and income. Minority groups, such as African Americans and individuals with an Asian or a Latino surname, are oversampled to ensure that minority groups are covered in each county.

Data from the OFHS, which is conducted by the Ohio State University with funding from multiple government agencies, are accessible through public-use data files and confidential research data sets for restricted use. Researchers must contact the Ohio Colleges of Medicine Government Resource Center to obtain permission to use the confidential data sets. Further information about the survey can be found at http://grc.osu.edu/ofhs.

Hawaii Health Survey (HHS) The Hawaii Health Survey aims at providing the Hawaii Department of Health, other agencies, and the public with data on health services, programs, and health issues. This survey was originally initiated in 1968 and modeled after the NHIS. Until 1996, interviews had been conducted in person, but in 1996 it became a telephone survey. Hawaii Health Survey data are used in public health policy analysis and development within Hawaii, and by local jurisdictions for which samples are available.

Surveys are conducted annually (since 1968); information is collected from approximately 6,769 adult respondents, aged 18 and older, on behalf of about 20,000 individual household members. Respondents are not randomly selected; an adult who is identified as the most knowledgeable about his or her household is selected for an interview in English about all household members. The sample is adjusted and weighted for subareas of Honolulu (city and county), Hawaii, Kauai, and Maui.

Specific questions related to CVD, COPD, asthma, and/or diabetes include questions on whether the person has been diagnosed as having arthritis, asthma, diabetes, high blood cholesterol, hypertension, or cancer (questionnaires are not publicly available). Other Hawaii Health Service questions include behaviors and risk factors (overweight and obesity), health insurance coverage, child care, access and use of health care, other chronic conditions, mental health, and food insecurity. The survey includes detailed information on age, gender, race/ethnicity, household income, education, and household size. Selected data tables are available online. Public-use data files are not available, although publications of researchers using these data are. Further information about the survey is available at http://www.hawaii.gov/health/statistics/hhs/index.html.

Local Surveys

Some counties and cities have established their own periodic health surveys. Los Angeles County has conducted periodic surveys of its population, and New York City has gone farther than any other local jurisdiction by developing surveys of adults from all five boroughs as well as a one-time local Health and Nutrition Examination Survey (http://www.nyc.gov/html/doh/html/hanes/hanes.shtml). These surveys are designed to meet state and local needs for population health data to guide efforts to address chronic disease and other domains of health disparities.

New York City (NYC) Community Health Survey (CHS) The NYC CHS is a local health survey that collects information on health risk behaviors, health conditions, preventive health practices, and healthcare access, primarily related to chronic disease and injuries. This survey was initiated in 2002 and is conducted annually. NYC CHS data are used for policy development, program evaluation, and advocacy within NYC and at the neighborhood level. They are also used for research and surveillance of racial, ethnic, and other social disparities in health. The survey is funded by the NYC Department of Health and Mental Hygiene. There are no federal funds to support this survey.

The study sample consists of a stratified quota probability sample of households with telephones in the city (approximately 10,000 participants per year). This design uses random-digit dialing to enroll sufficient quotas of participants from different ZIP codes. One adult, age 18–99, per family is randomly selected to participate. Interviews are conducted 10 months of the year. Information is collected on self-reported prevalence of hypertension, high cholesterol, diabetes, and asthma, and on aspirin use. Information is also collected on physical activity; nutrition and weight control, including consumption of fruits and vegetables; tobacco use and alcohol consumption; and access to, and use of, healthcare services. Self-reported sociodemographic data are collected, including age, sex, race/ethnicity, nativity, marital status, education, employment, and household income. The large survey size and diverse urban population allow for the ability to examine and describe social disparities in health and health care.

NYC CHS provides annual public-use data files through its website, http://www.nyc.gov/doh/mycommunityhealth/, as well as survey instruments and other documentation materials, sets of trend analysis tables for the states and the nation, and sets of demographic-specific tables for estimates of risks and conditions, including bar charts for comparison of areas or survey years. More than 40 peer-reviewed journal articles have been published using NYC CHS data.

Strengths, Limitations, and Opportunities of Population Health Surveys

Health surveys of the general population provide valuable information about the prevalence and distribution of chronic diseases as well as about associated risk factors that may contribute to them and their consequences. Major strengths are the breadth of information they offer and the ability to achieve representativeness through careful sampling. Such information may be helpful in tracking distributions, changes in rates, and comparisons among subgroups. Population surveys are especially valuable because they are based on nonclinical samples, including people who may not have been included in disease reporting systems or registries. Furthermore, population surveys provide valuable data for analyses of disparities in health and healthcare related to the social characteristics they measure (e.g., race, ethnicity, income, geographic area of residence, and other social characteristics). Comprehensive surveys enable researchers to include in their analyses other issues that may be relevant to chronic diseases, including mental health status, health behaviors, and other health and social factors.

Most population health surveys that collect data on chronic conditions use samples drawn from a general population, but they do not include residents of nursing homes or other institutions, many of whom may have the condition of interest. In-person surveys are widely considered to be most inclusive of the population because they select people based on where they are rather than whether they have a telephone or respond to mail surveys, and because they often have high response rates.

Challenges exist in conducting population health surveys. The high cost of conducting in-person surveys has motivated the use of telephone surveys, which can reach a larger and geographically more dispersed sample at far lower cost per completed interview. As the field of telecommunications has changed in the past two decades, telephone surveys have begun sampling both persons with landlines and those who rely on cell phones. Nonetheless, with call screening technologies widely available and with increasing demands on people's time, telephone surveys have seen steep declines in response rates, eroding public confidence that they include a truly representative sample of the population. Survey methodologists are struggling to develop modes of survey data collection that cover all relevant sectors of the population, including those more responsive to web-based communication than telephone, as well as persons from all relevant races, ethnicities, income, and education levels.

Good chronic disease surveillance requires valid and reliable measurement of the condition. Many population surveys rely exclusively on respondent self-report to questionnaire items, which is perhaps most valid for measuring many health behaviors, mental health conditions, perceived barriers to accessing health services, and reporting of symptoms. However, surveillance of chronic disease also requires reliable examination and laboratory data, which are expensive to collect within the context of a population survey. Examples of population health surveys that rely on respondent self-report include the NHIS, the YRBSS, the BRFSS, and many comprehensive state and local health surveys, such as the CHIS, the OFHS, and NYC CHS. Examples of population health surveys that employ both in-person clinical and laboratory examinations as well as respondent self-reports are the NHANES, SHOW, and NYC HANES.[4]

The CDC's BRFSS and YRBSS are two examples of surveys that have advanced chronic disease surveillance capacity at the state level through the efficient leverage of federal resources, and in some cases they include local sampling. Likewise, dedicated state surveys such as CHIS and the OFHS demonstrate that state and private funds can be harnessed for expanded data collection that is highly responsive to a wide range of local and regional stakeholder needs. Similar synergies are needed to (1) link state and local BRFSS data to data sources that provide neighborhood environmental information; (2) promote coordination of state and local surveys with federal surveys to enhance the comparability of measures and resulting data; (3) support state and local efforts to collect examination and laboratory data as part of population surveys; and (4) increase timeliness of national and state survey data releases. Researchers generally make good use of surveillance survey data when data files are available from the surveys. However, most surveys could usefully expand their dissemination strategies and resources to facilitate and encourage the use of surveillance survey data for policy development and advocacy, particularly at the state and local levels.

[4] See http://www.nyc.gov/html/doh/html/hanes/howto.shtml (accessed August 2, 2011).

Registries

One of the most powerful tools employed for the recording of chronic diseases is the use of a register, a place in which discrete facts are precisely recorded. The use of a register as a tool was first described nearly a millennium ago in England in the Domesday Book, used to ascertain royal land holdings and revenues (Weddell, 1973). The passing of the *Census Act* in Great Britain followed in 1800 (Weddell, 1973), enabling the creation of a means to collect complete basic demographic data about a population.

A registry, as it pertains to health care, is defined as "a file of data concerning all cases of a particular disease or other health-relevant condition in a defined population such that the cases can be related to a population base" (Last, 2001). The Agency for Healthcare Research and Quality (AHRQ) (2010) has defined a patient registry as "an organized system that uses observational study methods to collect uniform data (clinical and other) to evaluate specified outcomes for a population defined by a particular disease, condition, or exposure and that serves predetermined scientific, clinical or policy purpose(s)."

Types of Registries

There are several distinct types of health-related registries that compile unique information and context. Examples of patient registries defined by AHRQ include product registries (device or pharmaceutical), health service registries (relating outcomes to exposure to a healthcare service), disease or condition registries (in which the presence of the disease or condition becomes the inclusion attribute), or combinations of the above. Weddell (1973) classified registries along a somewhat different taxonomy, including as major categorizations specific information registries, disease-based registries, treatment registries, aftercare registries, at-risk registries, and resource registries. Although both of these classification systems are equally appropriate, the committee has chosen to use the Weddell categories in the following description of registries.

Specific information registries collect and record information pertaining to specific and defined conditions, enabling calculation of incidence and prevalence of the condition. Examples of specific information registries might include information on a specific medical condition, such as congenital malformations, or perhaps it might include attempts to monitor health practice in response to new legislation. *Disease-based registries* are, as the category implies, related to a specific disease condition, with case definitions clear enough to be recorded and catalogued. Examples of disease-specific registries might include conditions such as ischemic heart disease, COPD, specific types of cancer, schizophrenia, blindness, etc. (WHO, 1969). Such registries can serve as a powerful means of observing and recording the natural history of a disease, the response over time, and the effectiveness of various treatments. They can also accrue information pertaining to the safety or harm of various treatments, the care provided, care patterns, quality of care, disparities in care provision or outcomes, and other information (Gliklich and Dreyer, 2007).

Treatment registries require an ongoing list of all individuals who have received a particular treatment, along with follow-up information. These types of registries can be procedure based, for instance, applying to those who have had certain types of surgical procedures such as carotid endarterectomy. They can be based on medical therapy, such as use of a new inhalational agent, or related to use of specific devices. An important modern-day example of the latter includes registries based on implantation of cardioverter-defibrillators. Participation in such a registry is a requirement for reimbursement for these expensive and potentially life-saving devices.

Aftercare registries record information pertaining to care regimens, such as institutionalizations or hospitalizations. *At-risk registries* consolidate information on individuals with known or perceived risk factors for a disease, such as for those who smoke (creating risk for chronic pulmonary disease, cardiovascular disease, and cancer) or for those who have elevated levels of blood cholesterol, creating a risk for cardiovascular disease. Occupational health risk-exposed individuals or individuals with medical hazards exposures can also be tracked via this type of registry. A *resources registry* conglomerates information related to a specific resource of interest, such as blood or tissue banking resources. Genetic repositories (actual DNA banks or virtual sequence repositories) could also be considered to fall into this category of resource registries.

Many registries are relevant to cardiovascular and pulmonary diseases. Specific examples of registries available to collect information on cardiovascular disease include the Cardiac Arrest Registry to Enhance Survival (CARES),[5] the Cardiovascular Research Network (CVRN),[6] the National Cardiovascular Data Registry (NCDR),[7] the International Registry of Aortic Dissection (IRAD), the Global Registry for Acute Cardiac Events (GRACE),[8] various third-party, payer-based cardiovascular disease registries such as BMC[2] (sponsored by Blue Cross), and the Paul Coverdell National Acute Stroke Registry. Though acute lung disease registries and tissue banking (e.g., Acute Respiratory Distress Syndrome Clinical Network, or ARDS Net[9]) have become important tools to understand and combat acute pulmonary disease, registries are more limited in the area of chronic lung disease. The COPD Foundation, in conjunction with the National Jewish Medical & Research Center in Denver, has established a registry of individuals diagnosed with COPD and their families who have indicated a willingness to participate in COPD research. Additionally, there are local registries, such as the Ohio State University COPD Registry, that seek to identify factors that contribute to the development of COPD.

Strengths and Limitations

Disease-specific registries are useful tools for capturing patient-specific data for individuals who have selected conditions. Registries have significant advantages. The most important is prospectively collecting the exact surveillance data needed in the exact format required. At the most fundamental level, registries allow calculation of incidence rates. If the cases are regularly followed up, a registry can also provide information on remission, exacerbation, prevalence, and survival. Registries are often used in chronic disease control, thereby enabling data collection on risk factors and prevention programs, diagnosis, treatment approaches, and mortality.

A most interesting potential use of registries is in the translation of information into gains in understanding and treating diseases. Although clinical trials are immensely useful in defining utility (or futility) of a given treatment in a highly defined population, registries provide a more real-world application and data source, accounting for wide variation in human beings, conditions, practice settings and patterns, environmental exposures (both known and unknown), and hidden biases that may creep into clinical trials when enrolled subjects do not fully represent a population at risk for or affected by a disease. Registries can therefore be the basis for "observational" studies, providing important inferential data regarding disease causality or treatment efficacy, futility, or toxicity. This can provide pivotal information leading to the improved design of a subsequent clinical trial.

The distinction between surveillance- or registry-based information and clinical trials can be marked. Clinical trials entail a population of patients who meet entry (and fail to meet exclusion) criteria. Surveillance or registry data, on the other hand, are more reflective of community or population settings. In fact, creation of community-based registries can aid in the diffusion of therapeutic advances into clinical practice; one example is the use of beta blockers for the treatment of a chronic cardiovascular disease such as heart failure (Franciosa, 2004).

As for disease surveillance, national registries can be used to improve the quality of health care. Registry information on a national level can be gleaned from administrative data sets, such as those used by the Centers for Medicare & Medicaid Services (CMS) or from large third-party payers. Such information can come in the form of hospital or practitioner report cards, or other health reporting measures that lead to changed practice and improved outcomes. For example, a number of European countries have developed national disease registries. In Portugal, such registries include those for acute coronary syndromes, percutaneous coronary interventions, and stroke; these registries contain both clinical and administrative data (Sousa et al., 2006). Sweden has more than 50 voluntary disease-based registries, developed by consensus of a given medical specialty. The registries are used to make comparisons over time so that performance indicators can be established, and hospitals may benchmark against a national database (Sousa et al., 2006). In the United Kingdom, the National Health Service has developed registries to provide open benchmarking of clinical outcomes and performance of specific institutions against a

[5] See https://mycares.net/ (accessed August 2, 2011).
[6] See http://www.cvrn.org/ (accessed August 2, 2011).
[7] See http://www.ncdr.com/webncdr/common/ (accessed August 2, 2011).
[8] See http://www.outcomes-umassmed.org/grace/ (accessed August 2, 2011).
[9] See http://clinicaltrials.gov/ct2/show/NCT00000579 (accessed August 2, 2011).

national comparator (Sousa et al., 2006). Not unlike the current patchwork of chronic disease surveillance systems in the United States, European registries are often diffuse, lack interconnectivity, and lack certain usefulness that might be better achieved through nationwide harmonization.

Despite the advantages of using registries for surveillance, there are some inherent limitations. One of these limitations pertains to bias, which may creep unrecognized into data sets, and which may result in misleading conclusions. Bias in registry composition and analysis can take several forms, including that related to patient selection into the registry, unmeasured confounders, and misclassification of patients entered into a registry. It is important to understand how even registries that apparently take into account all known cases of a disease or procedures may still be confounded by bias of the sorts listed above when used for surveillance.

Aside from biases that may affect case definition, inclusion, and other material information for registries, another confounder is that subsequent data on registry patients may be missed; for example, data will be missed when registry patients visit healthcare providers not participating in the registry. Yet another potential limitation of registries is that the ability to investigate secondary questions is limited. Questions that arise after a given registry is established might prove difficult to investigate if needed data were not prospectively collected. This would be especially true when healthcare providers begin using new tests and treatments, or adopt new terminologies.

Another potential pitfall in using registries for surveillance relates to the fact that collecting registry data is not central to healthcare delivery. Collecting and entering data into the proper forms and format requires time and effort beyond the usual healthcare delivery processes. Because resources devoted to the registry often do not immediately benefit the practice or its patients, clinicians may be reticent to register patients or collect and record data on busy days, and busier clinicians may be less inclined to participate in registries altogether. The mandatory nature of some registries (e.g., those for implantation of internal cardioverter-defibrillators) tied to reimbursement is one approach to mitigate this potential pitfall.

Summary

A number of types of registries are related to health care. They collect and record information about specific conditions, treatments, outcomes, or populations. Registry data have the potential for various types of biases more than survey data do. On the other hand, registry data can provide more specific insights into disease-specific treatment effectiveness (or futility), and they help in the area of evidence-based medicine by promulgating diffusion of knowledge, treatments, and technology into community practice. Registry data fall somewhere in the evidence-based spectrum between clinical trials and surveillance. Clinical trials define prescriptive and proscriptive entry criteria. In surveillance efforts, data accrue from all (or unselected representative members) of a defined population. One can see that there is a complementarity among the three approaches—surveillance data, registry data, and clinical trials—each providing different insights, degrees of bias, and applicability to a given disease or treatment or to a particular setting. There is inherent value in each approach, with each type of data providing input into the hierarchy of evidence needed to improve healthcare outcomes.

Cohort Studies

National surveillance in the United States is largely cross-sectional and includes the household surveys such as the NHIS and the NHANES (both conducted by the NCHS) and the BRFSS (conducted by the CDC). These studies provide rapid information about national or regional populations within the United States and allow inferences about changes in disease rates or changes in prevalence in subsequent surveys. Another approach to surveillance is the cohort study. The cohort design can be either prospective or retrospective. Retrospective cohort studies are less costly, shorter in duration, and useful for examining prior exposures; however, the resulting information is less complete and accurate than through the prospective approach. Familiar examples of this approach include the Framingham Heart Study, Atherosclerosis Risk in Communities Study (ARIC), Cardiovascular Health Study (CHS), Coronary Artery Risk Development in Young Adults Study (CARDIA), Rancho Bernardo Study (RBS), and Strong Heart Study (SHS). A more comprehensive list of cohort studies is provided in Appendix A.

Framingham Heart Study

The Framingham Heart Study began in 1948 to secure epidemiological data on arteriosclerotic and hypertensive cardiovascular disease. The initial cohort included 5,209 persons aged 30–62. Data were collected using interviews and measurements from in-person examinations, biomarker collection, health history updates by mailed questionnaire or telephone interview, and follow-up medical records from healthcare providers. Framingham Heart Study data are available through research proposals submitted online and approved by relevant review committees. Variables are posted on the study website (http://www.framinghamheartstudy.org/risk/coronary.html).

Survivors from the original cohort continue to be followed, as do their children and grandchildren. An assessment by D'Agostino and colleagues (2008) that included 8,491 participants from the original Framingham Heart Study and the Framingham Offspring Study demonstrated that a sex-specific multivariable risk factor algorithm could be easily used in primary care to quantify general CVD risk and specific CVD risk (coronary, cerebrovascular, and peripheral arterial disease and heart failure).

The original study design for Framingham could not be used to yield prevalence rates, but it was well suited for the estimation of incidence rates. The findings could not be reliably generalized to other ethnic groups, as the cohort was primarily composed of white individuals. Investigators have also speculated that participation in periodic examinations may have motivated Framingham subjects to modify risk factors (Lloyd-Jones et al., 2002). The major contribution of the study has come in detailing incidence rates, in particular relating risk factors, and with its careful longitudinal follow-up it has near complete data on the development of diseases. Furthermore, much of these data were collected when medical interventions such as antihypertension therapies were not actively used. This has provided a "natural history" of the risk factors and the diseases that followed them. All this is ideal for the estimation and study of incidence rates. Few other studies have been in such optimal positions (http://www.framinghamheartstudy.org/about/background.html).

The Atherosclerosis Risk in Communities Study (ARIC)

ARIC is a prospective study conducted in four U.S. communities (Forsyth County, North Carolina; Jackson, Mississippi; Minneapolis suburbs, Minnesota; and Washington County, Maryland) to investigate the etiology and natural history of atherosclerosis in middle-aged adults. It also measures variation in cardiovascular risk factors, medical care, and disease with respect to race, sex, place, and time. ARIC includes a cohort component composed of 15,792 persons aged 45–64, and a community surveillance component. The cohort component serves to validate incidence rates, while community surveillance enhances the generalizability of cohort findings. A data request must be submitted to the National Heart, Lung, and Blood Institute (NHLBI) to use ARIC data for research and data analysis. ARIC includes a series of quality assurance and quality control protocols that include steps such as repeated measurements.

White and colleagues (1996) reported strengths and weaknesses of the ARIC study design with regard to CHD. In comparison to community surveillance, they observed that the cohort design "permits the more complete and standardized characterization of a broader range of CHD endpoints, including angina and, via repeated ECGs [electrocardiograms] obtained during repeat clinic visits, clinically unrecognized myocardial infarction." Other advantages are a more accurate classification of incident versus recurrent CHD events, intensive measurement of risk factors every 3 years, and increased understanding of morbidity and mortality trends by observing changes in risk factors over time. The weaknesses include insufficient size to precisely characterize CHD rates and trends, and volunteer bias that may limit generalizability to the reference communities.

Cardiovascular Health Study (CHS)

CHS is a prospective population-based cohort study of risk factors for CHD and stroke in adults aged 65 and older; 5,201 participants were recruited from four field centers (Forsyth County, North Carolina; Sacramento County, California; Washington County, Maryland; and Pittsburgh, Pennsylvania) in 1990, with an additional 687 predominantly African American participants recruited in 1992. The baseline examinations included a home

interview and a clinical examination that assessed traditional CVD risk factors as well as measures of subclinical disease, including carotid ultrasound, echocardiography, electrocardiography, and pulmonary function (http://www.chs-nhlbi.org/CHSDesc.htm). These examinations permitted evaluation of CVD risk factors in older adults, particularly in groups previously underrepresented in epidemiologic studies, such as women and the very old (Fried et al., 1991). CHS data are available with proposals approved by the CHS Publications and Presentations Committee and the Steering Committee; they are also available as a limited-access data set with NHLBI.

Coronary Artery Risk Development in Young Adults (CARDIA)

The CARDIA Study examines the development and determinants of clinical and subclinical cardiovascular disease and its risk factors in young adults. It began in the mid-1980s with a cohort of 5,115 black and white men and women aged 18–30 residing in four cities: Birmingham, Alabama; Chicago, Illinois; Minneapolis, Minnesota; and Oakland, California. The data that have been collected include blood pressure, cholesterol and other lipids, glucose, physical measurements, lifestyle, dietary and exercise patterns, behavioral and psychological variables, medical and family history, and other chemistries. Subclinical atherosclerosis was measured via echocardiography during years 5 and 10, computed tomography during years 15 and 20, and carotid ultrasound during year 20 (http://www.cardia.dopm.uab.edu/overview.htm). Use of CARDIA data requires approval from the Publications and Presentations Committee and affiliation with a CARDIA-approved investigator. A data repository data set (formerly known as Limited Access Dataset) can be requested directly from NHLBI.

Pereira and colleagues (2002) used CARDIA to examine the associations between dairy intake and incidence of insulin resistance syndrome. The authors noted that the main limitations of their study were related to the observational nature and potential for residual confounding. The strengths included the longitudinal design and (with regard to the diet history method), the comprehensiveness, the interviewer-administered format, the suitable time frame for capturing habitual diet without exacerbating recall error, and the applicability to populations differing in social and cultural characteristics.

The Rancho Bernardo Study

The Rancho Bernardo Study began in 1972 as one of 12 North American Lipid Research Clinic (LRC) Prevalence Studies designed to describe the prevalence of hyperlipidemia in different populations. An initial goal was to study gender and diabetes as risk factors of cardiovascular disease. The LRC was funded by the NHI (now the NHLBI) through an 8-year follow-up and is now in its 39th year of receiving support from the National Institute of Diabetes and Digestive Kidney Disease and the National Institute of Aging.

The LRC site was located in Rancho Bernardo, an almost entirely white suburb of San Diego. A survey was used to identify residents aged 30 and older; 82 percent (2,500 men and 2,900 women) enrolled. Survivors are invited to be seen in the research clinic seen every 3–5 years and are followed every year by mail or phone for vital status. The RBS added the classic CVD risk factors, including diabetes, to the baseline visit; subsequently it broadened its scope to include many other common exposures and chronic disease outcomes. Most risk factors, including psychosocial variables, are measured at every visit. Multiple novel risk factors, pulmonary function using spirometry, coronary artery calcium, carotid ultrasound, and peripheral arterial disease were measured at least once. Data from the RBS are available to approved investigators and have been used in more than 400 publications.

Most subjects were white and had at least a high school education, so results may not be generalizable to other groups. Multiple evaluations, with ethically mandated reports of identified risk factors or health problems, may lead to interventions, improve prognosis, or reverse causality. The strengths of the study include excellent baseline prevalence data in the era preceding widespread use of effective blood pressure or lipid-lowering medications, and > 95 percent follow-up to 2008 for clinical and fatal CVD and multiple comorbidities.

The Strong Heart Study

The Strong Heart Study (SHS), which began in 1988, is a longitudinal population-based study of CVD and its risk factors in American Indians from three field centers in Arizona, Oklahoma, and South and North Dakota. There are two cohorts in the SHS: an initial sample of 4,549 American Indian men and women, age 45–74 years, and a set of 3,838 extended family members aged ≥ 15 years in 94 families, including 574 from the initial cohort. The initial cohort (62 percent of total population aged 45–74) was first examined in 1989–1992. The survivors were reexamined in 1993–1995 and 1998–1991, and the family cohort was first examined in 2001–2004 and reexamined in 2006–2009. Every examination included a personal interview and a thorough physical examination. Questions and procedures that related to CVD, chronic pulmonary disease, asthma, and diabetes included medical history, personal health habits, EKG, echocardiogram, carotid ultrasound, pulmonary function testing, and laboratory tests of lipids, glucose, insulin, albuminuria, and others (http://www.strongheart.ouhsc.edu). A total of 3,798 family members were included in genome-wide linkage scans. In addition, an annual CVD mortality and morbidity surveillance using medical records and hospital discharges has been ongoing since the beginning of the study. The longitudinal data can be used to estimate prevalence and incidence of CVD and its risk factors in the American Indian population. SHS data are available with proposals approved by the SHS Publications and Presentations Committee and the Steering Committee.

Strengths and Limitations

In general, the prospective cohort design offers several advantages, including the ability to provide incidence rates, determine a temporal sequence of events (exposure precedes disease), and examine multiple outcomes from the same exposure simultaneously. Additional advantages of the cohort design are the emphasis on systematic data collection and uniformly conducted measurements. A major weakness is the potential for differences between study volunteers and the general population (Shlipak and Stehman-Breen, 2005). Additional disadvantages include subject attrition, inability to produce prevalence data, and relative expense.

Health Services Data

Data drawn from health services encounters or medical records can be used to understand healthcare access; identify services that people with chronic conditions receive, including patient visits, examinations, and laboratory and imaging studies; and examine healthcare quality and costs. These data are valuable in chronic disease surveillance when they are based on systematic recording of information by trained professionals; they are less valuable when the recording of data is less uniform and is based more on subjective professional judgments regarding what to record about the person's condition. Two types of health services data are claims data and medical record data obtained from manual chart abstraction or emerging electronic health records (EHRs).

Claims data (including medical, dental, and pharmacy claims) can be used to enumerate each encounter or service used by a person. It can be collected for hospitalizations, outpatient visits, public program coverage, or private health insurance. Claims data may include information that is sufficiently detailed to analyze the incidence rate of a chronic condition, the types of services patients receive, and the social characteristics of people who receive services for the condition. Claims data may also include geographic identifiers for persons or service providers and may be used to map geographic patterns of the incidence of hospitalizations, other services provided, and healthcare costs, which can be used in analyses of healthcare disparities.

Data abstracted from medical records and EHRs can provide a detailed record of the process of health services for persons with chronic conditions. (For a more detailed discussion of the use of electronic medical records in surveillance, see Chapter 6.) Such data can be used to assess quality of care provided to persons with chronic conditions and, if they include characteristics of the individual patients, the data can be used to assess disparities in care received. These data can be abstracted for use in registries (as discussed earlier in this chapter), for combination into data sets such as the Healthcare Cost and Utilization Project, or for surveys such as the National

Hospital Discharge Survey, the National Ambulatory Medical Care Survey, and the National Hospital Ambulatory Medical Care Survey, all of which are discussed below.

Claims Data

Claims data can be used to collect information on hospital utilization. Such data are largely collected and reported by state and federal agencies. States use standardized methods developed by AHRQ to use these data to report on hospitalization rates and mortality.

Medicare Part A claims data, also known as MedPAR or inpatient standard analytic files, are one of the most readily available and widely used sources of data on hospitalizations in the United States. All U.S. adults aged 65 and older who have paid Social Security payroll taxes for at least 10 years or who were the spouse of such a worker are eligible, as well as those who are permanently disabled or have end-stage renal disease (ESRD) or amyotrophic lateral sclerosis (ALS) are eligible for Medicare Part A. Medicare claims data are particularly useful because they are nationally representative and longitudinal for all enrollees in the traditional Medicare fee-for-service program, representing about 35 million beneficiaries.

Clinical data on Medicare hospital claims are limited to 10 diagnoses and 6 procedure codes, as defined by the International Classification of Diseases, 9th Revision-Clinical Modification (ICD-9-CM). The first or "principal" diagnosis is the reason determined at discharge as the main reason for a patient's admission to the hospital. Medicare Part A claims also include patients' Medicare identification number, a hospital identifier, and basic demographic data including age, sex, and race. Strengths of Medicare Part A data for chronic disease surveillance include the ability to link hospitalizations longitudinally for individual patients and to link to Medicare Part B data to assess physicians' services and ambulatory care before and after hospitalizations. Limitations of Medicare data for monitoring cardiovascular and pulmonary hospitalizations include the very limited data on patients under age 65 (i.e., only those with permanent disabilities, ESRD, or ALS) and the lack of data on patients enrolled in private health plans through the Medicare managed-care program known as Medicare Advantage. With the growing need for data to evaluate health system performance and public health policy, a number of states are developing all-payer claims databases (Love et al., 2010).

Although administrative claims data are useful at the macro level to describe patterns of use and mortality, a number of limitations are inherent in the use of administrative data that need to be considered in the interpretation and use of these data. These limitations include coding errors, limited clinical information, and diagnostic misclassification, which include underdiagnosis, overdiagnosis, and misdiagnosis common for cardiovascular and chronic lung diseases. Although the specificity of diagnostic algorithms shows promise for selected applications (Mapel et al., 2006; Yarger et al., 2008), their sensitivity and positive predictive value may be low (Rector et al., 2004; Singh, 2009). Moreover, variations in patterns of diagnostic practices may further bias claims data (Song et al., 2010).

Healthcare Cost and Utilization Project

Another widely used source of data on hospitalizations is the federal Healthcare Cost and Utilization Project (HCUP) maintained by the Agency for Healthcare Research and Quality (http://www.ahrq.gov/data/hcup). The HCUP family of data sets includes the State Inpatient Datasets (SID) and Nationwide Inpatient Sample (NIS). The SID includes data from 42 state data agencies that submit hospital discharge abstracts from all hospitals in their respective states in a standardized format. The SID includes approximately 26 million discharges per year, representing about 90 percent of all acute-care discharges in the United States annually. A closely related database is the NIS, which includes 8 million discharges per year from a sample of over 1,000 hospitals in the SID, representing about 20 percent of all U.S. hospitals. Data from the SID and NIS, respectively, can be used to estimate hospitalization rates in selected states and nationally for cardiovascular disease, chronic lung disease, and other major conditions.

Strengths of these data include information on patients of all ages covered by all payers (including the uninsured). Limitations of the SID and NIS include the inability to link hospitalizations for individual patients

because of the lack of unique patient identifiers that are consistent across hospitals, thereby precluding the calculation of true population-based rates of hospitalizations for specific conditions.

National Hospital Discharge Survey

The Centers for Disease Control and Prevention has been conducting the National Hospital Discharge Survey since 1965 (Hall et al., 2010). This is a voluntary survey of a national sample of hospitals, which included 422 in 2007, that describes patient and hospital characteristics, hospital discharge diagnoses, and procedures. Moreover, the longitudinal design allows monitoring of trends in use.

State Cardiac Procedure Databases

Surveillance of hospitalizations related to Coronary Artery Bypass Graft (CABG) or Percutaneous Coronary Interventions (PCI) procedures can also be conducted with specialized databases mandated by selected states, including California, Massachusetts, New Jersey, New York, and Pennsylvania, to monitor risk-adjusted outcomes in all nonfederal hospitals that perform cardiac surgery procedures; only Massachusetts and New York monitor outcomes after PCI. Strengths include abstraction of key clinical variables; rigorous data adjudication; inclusion of all adults, regardless of payer and insurance status; linkages to billing data; and for some states, ability to monitor outcomes longer. Limitations include a focus on inpatient hospitalizations and lack of patient-reported outcomes such as functioning.

Administrative Claims and Clinical Data

Multiple sources of data are available on the quality and safety of hospital care in the United States, including self-reports by patients and physicians (Davis et al., 2010; Jha et al., 2008), administrative claims data, and clinical data (Chassin et al., 2010; McCarthy et al., 2009). The focus of this overview is on the use of administrative claims and clinical data.

Since 2002, hospitals nationwide have been required to collect and report administrative and clinical data that are used in accreditation, CMS reimbursement, pay-for-performance, and public reporting of performance (Chassin et al., 2010; Lindenauer et al., 2007). These data provide information on clinical indicators of the processes and outcomes of healthcare delivery (Chassin et al., 2010). Currently hospitals provide data to the Joint Commission on 57 inpatient measures, including metrics on processes of care for acute myocardial infarction and congestive heart failure, but do not include metrics for chronic lung diseases. Of these inpatient measures, 31 are publicly reported. In addition, the CMS collects data on patient satisfaction (Jha et al., 2008) and clinical outcomes (e.g., readmissions and death) (CMS, 2009).

Overall, the results of the reporting and feedback on performance of process indicators have been positive, with substantial improvements in hospital performance since 2002 (Chassin et al., 2010; Jha et al., 2005; Williams et al., 2005;). Such improvements in hospital performance provide evidence on the feasibility and potential effectiveness of a larger chronic disease surveillance system; however, there are limitations to the current hospital surveillance activities (Chassin et al., 2010; Joint Commission, 2008; Pronovost and Goeschel, 2010). These limitations and experiences from the Joint Commission and CMS hospital surveillance provide a rich resource to guide further improvement of the existing system and development of a nationwide chronic disease surveillance system. The Joint Commission report, *Health Care at the Crossroads: Development of a National Performance Measurement Data Strategy* (2008), summarizes the current state of affairs. Many stakeholders are conducting performance measurement initiatives (e.g., National Quality Forum, Joint Commission, National Committee on Quality Assurance, American Medical Association–Physician Consortium for Performance Improvement, the AQA Alliance, the CMS, Hospital Quality Alliance, AHRQ, and the CDC), yet, as this quote from the Joint Commission demonstrates, these initiatives have limitations:

> *Most performance measurement efforts operate in isolation from one another to meet the specific needs of their sponsors. . . . Since data are collected and used in fragmented ways, they rarely provide a picture of the overall*

> *quality of performance for a specific clinician or organization, or how well patients fare, or the state of the public's health at-large.*
>
> *Insufficient attention has been paid to the data infrastructure that needs to be in place to support performance improvement activities. The framework for designing such a data infrastructure must address consumer expectations for data privacy, support a data highway that allows for data sharing and linkages, and operate under an agreed-upon set of rules and governance structure. These issues must be addressed expeditiously.* (Joint Commission, 2008)

A number of other limitations of the system need to be considered, including burden of data collection, inconsistent effectiveness of some indicators, insufficient standardization and accuracy, and gaps in measurement for some diseases and components of healthcare delivery (e.g., post-discharge and outpatient care) (Chassin et al., 2010; Joint Commission, 2008; Pronovost and Goeschel, 2010; Pronovost et al., 2007). Currently, for most hospitals the process is labor intensive with review and data abstraction from medical records. For example, an estimated 22 minutes are needed to abstract the record of a patient with congestive heart failure (Joint Commission website), which translates to more than 400,000 person-hours each year for U.S. hospitals (Fonarow and Peterson, 2009). The link between measures of process performance and health outcomes (e.g., rehospitalization, mortality) has been inconsistent (Fonarrow and Peterson, 2009; Jha et al., 2007; Mansi et al., 2010; Werner and Bradlow, 2006).

A major gap in the current CMS/Joint Commission hospital reporting and feedback is the lack of measures for some chronic lung diseases. Moreover, there is relative paucity of and scant evidence for the effectiveness of COPD-specific performance measures currently used by various organizations (Heffner et al., 2010).

National Ambulatory Medical Care Survey (NAMCS)

The NAMCS is a national survey that collects data on the provision and use of ambulatory medical care services in the United States. Data from the NAMCS are used in health services planning. Data are collected from patient visits to non-federally employed, office-based physicians. The survey is a systematic random sample of patient visits based on records and does not include anesthesiologists, pathologists, or radiologists. Information is collected in multiple stages. First, the survey samples primary sampling units, physician practices, and patient visits. Second, NAMCS selects practicing physicians from a master file from the American Medical Association and the American Osteopathic Association, stratified by specialty. Finally, physician samples are divided equally, and every subsample is randomly assigned to a week of reporting over the course of a year. Interviewers visit physicians in person prior to survey participation and show them how to fill out the forms. Data are collected on diagnosis of ischemic heart disease (IHD), heart failure, hypertension, hyperlipidemia, diabetes, COPD, and asthma, and risk factor data and laboratory measures are extracted. Patient demographic variables in NAMCS include age, ZIP code, sex, ethnicity, and race.

NAMCS allows approximate estimation of prevalence of diagnosed CVD, diabetes, and COPD and to assess resource use patterns. It is also useful for monitoring trends in ambulatory care for these conditions. However, data are restricted to those who seek care in participating physician-based offices and are thus not representative of the general population. Even for those settings, the survey does not include patients contacted by phone, contacts by house calls, visits made in institutional settings, and visits for administrative purposes only. This limits the use of this data source to generate reliable prevalence estimates or characterize health disparities.

National Hospital Ambulatory Medical Care Survey (NHAMCS)

Since 2001, the NHAMCS has collected data annually on ambulatory care services provided in noninstitutional, short-stay, and general hospital emergency rooms and outpatient departments as well as in ambulatory surgery centers. The survey does not include federal, military, and Veterans Administration hospitals. The survey covers all 50 states and the District of Columbia. A four-stage probability sample is used. Geographically defined areas are sampled, then hospitals within those areas are selected for survey. Clinics within outpatient departments are selected for the third stage; this includes all emergency service areas and ambulatory surgery locations. Finally, the survey samples patient visits from these locations (CDC, 2009a).

Specially trained interviewers visit the facilities before the survey to explain procedures, verify participation eligibility, develop a sampling plan, and instruct staff about how to gather information. Staff then complete the survey forms on patient visits using a systematic random sample within a randomly assigned 4-week reporting period. Survey instruments in NHAMCS are the patient record forms from three settings of care: the emergency department, the outpatient department, and the ambulatory surgery facilities. Data collected include diagnoses, diagnostic and screening services, procedures, medication therapy, types of providers seen, and disposition.

NHAMCS includes detailed questions on chronic diseases, including a checklist of chronic conditions, participation in disease management programs, and diagnostic and screening services. The survey also collects information on each medication prescribed, as well as information on health education and non-medication treatment.

The NHAMCS provides the most current nationally representative data on outpatient care in the United States. It is the longest continuously running, nationally representative survey of hospital ED and outpatient use, which are major sources of ambulatory preventive care for lower income and Medicaid patients, and of specialty care for people with other types of insurance.

Like the NAMCS, the NHAMCS is not representative of the general population; rather, it represents a population of active outpatients, and the sampling frame of NHAMCS is not well defined. In addition, the NHAMCS surveys are designed primarily to provide national estimates. Although estimates by geographic region (Northeast, Midwest, South, and West) and metropolitan statistical area status are available, meaningful estimates cannot be made on a state-level basis.

Vital Statistics

In the United States, all deaths are legally required to be reported to health departments in the state where they occur, and data from these reports serve as a critical source of information on mortality trends and patterns. While monitoring of all-cause mortality is complete and reliable, the quality and utility of surveillance for cause-specific mortality patterns varies depending on the cause of interest, in part due to the reporting and coding processes. In nearly all states, physicians are required to record underlying and contributing causes of death on the death certificate, which are then coded by trained nosologists at health departments using a standardized international classification known as the International Statistical Classification of Diseases and Related Health Problems (currently in its 10th revision) (WHO, 2010). These data are compiled at the state and local levels, then shared voluntarily with the National Center for Health Statistics.

Studies have shown CHD listed on death certificates to have relatively low sensitivity and specificity compared with medical chart review or autopsy findings, and the majority of studies suggest that death certificates overreport CHD mortality (Agarwal et al., 2010; Coady et al., 2001; Lloyd-Jones et al., 1998; Sington and Cottrell, 2002). For example, the ARIC study found that death certificates overestimated CHD deaths by 20 percent compared with a physician review panel (Coady et al., 2001). A study of Framingham Heart Study participants found that death certificates attributed 24 percent more deaths to CHD than a physician panel reviewing medical records (Lloyd-Jones et al., 1998). Differences between in-hospital versus out-of-hospital deaths also have been identified. A study in New York City identified 50 percent overreporting of CHD deaths on death certificates among in-hospital deaths in persons aged 35 to 74 (Agarwal et al., 2010), In contrast, studies in Olmstead County have identified 5 percent underreporting of out-of-hospital CHD deaths (and 10 percent overreporting of sudden cardiac deaths) (Goraya et al., 2000).

Cause of death tracking also does not accurately reflect burden of disease for COPD-related mortality. A number of studies have shown that patients with severe COPD may not have COPD listed on their death certificate, despite respiratory involvement noted in their charts (Camilli et al., 1991; Mitchell et al., 1971). Using the U.S. National Center for Health Statistics data, Mannino and colleagues (1997) found obstructive lung disease underestimated in studies looking only at the underlying cause of death.

While errors in coding do occur, most misclassification of cause of death occurs when the cascade of health events leading to the death is improperly or incompletely reported by the physician and administrators completing the initial death certificate. Few physicians are adequately trained in identifying underlying and contributing causes of death for certifying fact of death (Lakkireddy et al., 2004). Also, in most hospitals, the providers who

know most about the patient do not always complete the death certificate. Instead, available clinical and administrative staff members who may not know a decedent's medical history are filling out the cause of death information (Messite and Stellman, 1996). In addition, providers may not have all relevant patient information available at the time. Lack of information is a particular challenge with out-of-hospital, dead-on-arrival, outpatient, and emergency department decedents. Similarly, deaths that occur among older adults with multiple comorbidities are at particularly high risk for being misclassified.

Despite these limitations in misclassification, surveillance of CVD and chronic lung disease mortality is important to monitor reductions in the burden and impact of chronic diseases on population health and for assessing improvements in treatment and management. To increase their utility, cause of death recording needs to be improved. Training of medical residents, coupled with periodic retraining of practicing physicians on death certificate completion, can potentially improve the validity of cause of death recorded. Many states are now also adopting electronic death certification, a process that may introduce ongoing and potentially interactive training opportunities (Koppaka, 2010). Eventually the process may lead to automated updates in death certificates from medical records, potentially reducing physician misclassification. This has already undergone limited piloting in Iowa (Nangle, 2010). Electronic reporting of death certificates may also improve timeliness (Goff et al., 2007).

INTERNATIONAL CHRONIC DISEASE SURVEILLANCE

International data on trends in CHD mortality have been reported from the late 1960s through the mid-2000s (PAHO, 2002; Wei et al., 2010; Zhang et al., 2003). Mortality rates from CHD in some countries (e.g., Denmark, Australia, and Canada) have decreased but remained stable or increased in others (e.g., Hungary, Romania, and Korea) during this period. Few countries in Europe, Asia, Africa, or South America have local or regional CHD surveillance systems in place to systematically disentangle changes in CHD incidence from mortality rates over time, or the contribution of primary and secondary prevention efforts to changes in CHD mortality over time. A similar lack of data exists for monitoring changing trends in the population magnitude and impact of other chronic diseases, including diabetes, heart failure, pulmonary disease, and stroke. Moreover, contemporary data describing the incidence and death rates of cardiovascular disease—which can be used to systematically compare the changing magnitude and impact of these conditions among countries—are essentially nonexistent. (See Appendix B for a list of international data collection efforts.)

Due to the lack of standardized collection of CHD mortality and incidence data, and limited availability of comparative information from a multinational perspective, the World Health Organization initiated the Multinational Monitoring of Trends and Determinants in Cardiovascular Disease (MONICA) project more than two decades ago. This ambitious project, which has provided extensive international insights into the descriptive epidemiology of CHD, examined changes over time in the incidence rates of fatal and nonfatal acute coronary events and in the primary risk factors for CHD. Forty-one MONICA centers in 21 countries, with only one U.S. center, collaborated in these monitoring efforts. However, the last point for data collection efforts of this observational study was in the mid-1990s. The need remains for the contemporary tracking of CHD and other chronic diseases and their risk factors in representative community samples.

A limited number of community-based investigations have been carried out during the past 25 years in the United States, Europe, Scandinavia, Australia, and New Zealand. They examined changes over time in the incidence and death rates from acute myocardial infarction and out-of-hospital deaths attributed to CHD. Several of these studies are either quite dated or are no longer collecting data. Each of the major population-based studies in this area has shown a net decline in the incidence rate of acute coronary events over the varying periods examined, with estimated declines of approximately 2 to 3 percent.

A number of European countries have developed national disease registries. In Portugal, such registries include those for acute coronary syndromes, percutaneous coronary interventions, and stroke; these registries contain both clinical and administrative data (Sousa et al., 2006). Sweden has more than 50 voluntary disease-based registries, developed by consensus of a given medical specialty. The registries are used to make comparisons over time so that performance indicators can be established, and hospitals may benchmark against a national database (Sousa et al., 2006). In the United Kingdom, the National Health Service has developed registries to provide open bench-

marking of clinical outcomes and performance of specific institutions against a national comparator (Sousa et al., 2006). Not unlike the current patchwork of chronic disease surveillance systems in the United States, European registries are often diffuse, lack interconnectivity, and lack certain usefulness that might be better achieved through nationwide harmonization.

An example of nationwide harmonization comes from The Health Improvement Network (THIN), a primary care database composed of electronic medical records from 446 general practices throughout the United Kingdom. It contains nearly 7 million patient records (http://www.thin-uk.com/). This database has been used for the surveillance of CVD and chronic respiratory diseases (Donaldson et al., 2010; Feary et al., 2010).

In terms of COPD and chronic bronchitis, several large-scale international efforts have been carried out that have primarily assessed the prevalence rates of chronic pulmonary disease and its predisposing factors in population-based samples of adults residing in urban and rural settings; these studies have been carried out in a number of developed and developing countries of varying population size and characteristics. Many of these studies, however, were carried out in the distant past. Most have not provided information on the incidence rates of COPD and bronchitis and the major risk factors for these chronic conditions, and few have examined long-term trends—or changes over time therein—in morbidity, mortality, functional status, or use of different treatment regimens in persons with chronic pulmonary disease.

Lessons Learned from International Studies of CVD and COPD

A considerable amount of useful clinical, epidemiologic, and policy-related information has been obtained from the design and conduct of CVD, COPD, and risk factor registries as well as surveillance systems and observational studies that have been carried out in developed and developing countries over the past several decades. The growing burden of chronic diseases worldwide has resulted in a renewed emphasis on surveillance of chronic diseases in developing countries (Alwan et al., 2010). Despite the extensive amount of data collected and disseminated from these investigations, sustainability of these projects has been difficult due to funding constraints/concerns and continued interest on the part of the investigators and funding agencies.

On the other hand, a number of national disease registries and chronic disease surveillance programs have been conducted in a more cost-efficient manner, through the use of a unique personal identifier. The use of a personal health identifier has allowed for the linking of different computerized databases and files for the express purpose of bringing together patient demographic, medical history, clinical, treatment, and outcomes data, which has greatly facilitated the design and conduct of population-based surveillance studies. Indeed, several developing countries are also either utilizing at present, or considering utilizing, a unique patient health identifier.

Surveillance studies of CVD and COPD in both the United States and abroad have shown the feasibility and utility of these surveillance systems. Data from these investigations have provided insights into the descriptive epidemiology of these chronic conditions and their pre-disposing factors; hospital and long-term outcomes and factors associated with a good or unfavorable long-term outlook; and use of different management approaches that could be linked to different outcomes in future comparative effectiveness studies. These studies have shown the type of data that can be realistically collected in the context of these surveillance studies. Furthermore, they have provided insights into information that should be collected at a minimum and "wish list" type of information that might be collected either from direct personal interviews or computerized health databases.

Given ever-present economic uncertainties throughout the world, and the costs associated with initially developing, field testing, collecting information, and analyzing and disseminating surveillance-related findings, serious consideration needs to be given to streamlining the collection of pertinent data in future surveillance studies; strong consideration also needs to be given to the scientific and cost efficiencies associated with the use of a unique personal health identifier and use of standardized case definitions and data collection elements so that results can be compared within and across different countries, regions, and locales. More specialized surveys can be developed at the local, community, or state level to address more narrowly defined geographic and socioeconomic disparities in CVD and COPD with more detailed insights provided into high-risk groups and areas in need of enhanced surveillance and/or intervention.

CONCLUSION

As this chapter has discussed, there are several different types of data sources collecting surveillance information for specific conditions, treatments, outcomes, or populations. National and local surveys provide powerful tools to inform on self-reported chronic conditions, health behaviors that may help prevent chronic conditions or, alternatively, increase the risk of developing such conditions. They also provide valuable information on disease management. There are several limitations with these surveys, however, including the inability of national surveys to calculate reliable local estimates unless sampling is designed to generate local data sets, the inability to link anonymous surveys to other information (or from children to parents), the limited amount of information on risk factors and outcomes for chronic lung disease, and little information on receipt of clinical services.

Registries can provide detailed clinical, demographic, and treatment-specific information on disease or procedure-specific populations or insured populations for monitoring the quality and quantity of care provided. But many registries focus on specific clinical populations, and this may result in incomplete information if the patient or beneficiary accesses care outside of the healthcare system. Hospital-based registries also include detailed information about a hospitalization but often no follow-up data. Finally, the decision to include a patient in a registry can be subjective as this decision is typically made by a clinician.

Prospective cohort studies can provide critical information for surveillance through the collection of incidence rates of temporal events (including exposures) and of clinical and patient-reported outcomes. However, prevalence information cannot be measured beyond baseline. Moreover, because longitudinal follow-up (a major strength of cohort studies) is resource intensive, the number of subjects participating will be limited, preventing the study of rare events or the study of smaller subgroups such as counties.

Critical surveillance indicators are also available in health services research data. These include hospitalization and readmission rates at the national, state, and local levels. Healthcare surveys have the ability to provide prevalence rates for cardiovascular and chronic lung disease risk factors and some outcomes. While there is as yet no universally accepted interoperable data platform for electronic medical health record data, incidence and prevalence information would be available. However, like registry data, health services data exclude information extraneous to the healthcare delivery system.

The strengths of the current data systems for cardiovascular disease and chronic lung disease surveillance relate to the multiple and diverse informants used to monitor care—population-based surveys, patient-based surveys, provider-based surveys, and health services data. The weaknesses relate to the lack of integration of surveillance information obtained from the multiple informants and to the absence of focus on the life span of subjects. Another issue of concern is the lack of inclusion of incarcerated populations in current data collection efforts. According to Wang and Wildemann (2011), "mass incarceration affects not only disease surveillance but also studies of risk factors for the development of cardiovascular disease or tests of interventions to reduce disease in minority populations."

Despite the limitations of existing data collection systems, they are powerful tools for the collection of surveillance information. There are also emerging approaches to data collection that can enhance exiting efforts. The following chapter explores some of these emerging approaches.

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6

Levels of Surveillance and Emerging Data Sources

The previous chapter examined existing sources of surveillance information. This chapter explores the different levels and uses of surveillance information and emerging sources of surveillance data.

LEVELS AND USES OF SURVEILLANCE

The value of any surveillance system is ultimately realized through the timely and relevant information it offers and the decisions it informs and influences. To be successful, a surveillance strategy and system must engage potential decision makers and be relevant to the specific issues they confront—locally, nationally, and increasingly, globally. Information and knowledge needs vary by perspective, and resources are rarely available to support all needs. A nationwide surveillance system will involve consideration of a range of user groups. Effective patient care, health services management, public health, and health policy making is dependent upon reliable information about the individuals and populations being served and upon scientific knowledge about the health conditions being addressed and their effective delivery. This alignment of information has become increasingly critical with the implementation of healthcare reform and also with the growing global influence on national and local health.

The uses and impacts of systematic surveillance on decision making are a function of position in the overall health system. For example, a primary care or specialist *clinician* concerned with patient care will be influenced by clinical guidance from professional organizations and public agencies that is derived from longitudinal population analyses which are often focused on condition-defined subpopulations (e.g., patients with heart failure). A public health expert will look to surveillance data to understand disease burdens and their trends, to identify risk factors to intervene upon, and to monitor improvements in population health status.

A *manager* in a healthcare delivery system who must consider a range of possible clinical initiatives and allocate resources will look to surveillance data reflective of the population served to set priorities for staffing by various health professionals, development of patient and community educational programs, investment in services and facilities, and budgeting. To plan for clinical care, a manager of a health plan or Accountable Care Organization (ACO) will need information about the prevalence of CVD or COPD rates and risk factor rates of enrollees and the extent to which they correspond with rates in their communities. This information can be useful not only in allocating resources for clinical care; it will also inform the planning of educational and behavioral interventions that have potential to reduce costs or to improve health.

Researchers require data to make inferences about relationships between key variables (e.g., between race/ethnicity and treatment and outcomes). A key product of the proposed surveillance framework will be an increased ability to match research priorities to the needs of the population for health improvement.

Finally, a *policy maker*, such as a state or federal health officer, will seek perspective and support for public health programs and services, as well as new regulations or legislation based on demonstrated population needs, often involving multiple geographies. For example, a great deal of national, state, and local policy is based on national surveillance data on obesity, diet, and physical activity (including the impact of those health behaviors on obesity rates). First Lady Michelle Obama has led a national campaign to reduce obesity, encourage children and adults to eat more fresh produce, and increase physical activity. Her national campaign included highly visible public education events to promote home and community gardens, as well as efforts to mobilize voluntary health agencies and food manufacturing corporations to reduce the fat content and calories of their products. Public health leaders at the state and local levels have led similar public education and policy efforts as well as efforts to change food and beverage policies of school districts.

The types of information and level of detail required will vary among users of surveillance data. For example, physicians must apply available clinical guidance in the context of the individual needs of each patient. Such personalization may be best served by the ability to relate any patient to surveillance information collected and analyzed at a highly disaggregated level. Health system managers will typically need less granular information, although the degree to which surveillance information can be directly related to the population for which care is being provided will strongly influence its use. The researcher needs information on changing and contemporary trends in disease magnitude, management, predisposing factors, and acute and more long-term outcomes, including the utilization of healthcare services in order to identify topics worthy of further investigation for prioritizing research efforts, and also to generate hypothesis or to answer questions that may be addressed with surveillance data. Policy makers must balance multiple and often complex needs and perspectives, further testing the ability of surveillance systems to provide both applicable and actionable data. Data for policy development and advocacy must be relevant to the health issue that policy will target, the factors that are believed relevant to addressing the health issue, and the geographic location and demographic characteristics of the population involved.

These user examples (not an exhaustive list), the physician, the health systems manager, the researcher, the public health expert, and the policy maker may be found at the micro, meso, and macro levels (Table 6-1). Similar and often overlapping vertical hierarchies of role and professional decision-making data needs exist within other health-related perspectives, such as physician practice organization and governance, or among employer purchasers of health care. All these decision makers share the need for timely, relevant, and robust information about common populations of individuals, but they differ substantially in the granularity of their data needs and in how they process and leverage available data and information into action through the decisions they influence and control.

The different types of users of surveillance data access and use the data in different ways, as well as for different purposes. Researchers—whether they are clinical researchers or epidemiologists, behavioral scientists or health services researchers—are typically comfortable downloading micro data sets and analyzing them with appropriate data management and statistical software. Physicians and other clinicians benefit from the results of research studies that are transformed into guidelines by professional organizations and public agencies and then communicated widely to practitioners through peer-reviewed journals and other professional literature and conferences.

Policy makers and advocates as well as the news media similarly benefit from studies conducted with the data, using published findings to develop policies to address the health problem and the factors identified and supported by the studies. But policy audiences also benefit from being able to conduct descriptive analyses of the data to answer their own questions about an issue and to provide such descriptive evidence for the specific population—whether defined by demographic characteristics or geographic boundaries such as their district or county—for which they have some responsibility. Online data tools, such as CDC's WONDER,[1] which can be used to query many CDC data sources, and the California Health Interview Survey's very user-friendly and flexible *Ask*CHIS[2] query tool, are valuable ways to provide access to surveillance data for policy audiences as well as for others.

[1] See http://wonder.cdc.gov (accessed August 2, 2011).

[2] See http://www.chis.ucla.edu (accessed August 2, 2011).

TABLE 6-1 Levels and Users of Decision Making

Place and Roles	Place	Type	Who	What	Implementation Levers	Linkage to 2010 Reforms
Macro	• Federal • National • Nationwide	• Business coalitions • Benefit associations • National employer	• Federal government organizations • Medical society	Priority setting for • Regulation • Research and development • Objectives/ targets (e.g., *Healthy People 2020*)	• Legislation • Funding • Institutions (e.g., National Institutes of Health) • Communications	PPACA[a] • Comparative effectiveness • ACOs[b] ARRA[c] HIT/ONC[d] • Meaningful use
Meso	• Region • State • County • City • Community	• Regional/state employer • Small business	• State board • Medical society • Multispecialty medical group • Hospital medical staff • Public health workers • Local advocates	• Strategies • Programs and initiatives • Business planning and development • Performance reporting	• Budgets • Institutions and departments • Communications incentives	ACOs HIT funding • Beacon sites • Meaningful use • HIE[e] Chronic care Prevention
Micro	• Neighborhood • ZIP+4 • Home	• Schools • "Mom and Pop"	• Medical practice • Clinician • Family • Individual	• Interventions • Care and action plans • Outcomes	• Guidelines • Programs and initiatives • Communications • Payment or coverage	Insurance reform • Access • Free prevention services • Payment reform • Pay for performance • ACOs; medical home

[a] PPACA = *Patient Protection and Affordable Care Act*.
[b] ACO stands for Accountable Care Organization. According to the Medicare Payment Advisory Commission, "The defining characteristic of ACOs is that a set of physicians and hospitals accept joint responsibility for the quality of care and the cost of care received by the ACO's panel of patients" (MedPac, 2009).
[c] ARRA = *American Recovery and Reinvestment Act of 2009.*
[d] HIT stands for health information technology. ONC is the Office of the National Coordinator for Health Information Technology.
[e] HIE stands for health information exchange.

Surveillance design will require explicit trade-offs in what is included and which user needs are addressed as resources are constrained by time, funding, data accessibility, and acceptability of use. For example, cost constraints may result in sampling rather than assessment of an entire population or force a trade-off between detailed biological examinations versus self-reported information. In order to protect the confidentiality of individual patient data, sample size thresholds may be required for reporting.

Existing surveillance capabilities at best serve only a portion of the potential user continuum. Systems have generally been developed to inform policy (at the macro level) and guide priorities (at the macro and meso levels) while technical, confidentiality, and financial constraints have often limited the use of surveillance resources to more localized applications (including guidance of patient care and community policy making). Even then, effective surveillance research has influenced both the topics and specific recommendations of many clinical practice guidelines.

Strategies for improving surveillance, especially when coupled with constrained resources, must be dynamic and malleable to anticipate likely further progress in data collection, availability, use, and governance. In particular, electronic health information systems are rapidly expanding the diversity and accessibility of health data and are breaking down historical barriers to data collection and analysis. Insights into management and protection of individual patient data are allowing new uses of data collected for surveillance purposes, potentially providing timely and relevant decision support for an increasingly diverse group of users.

The roles and relationships among decision makers are also dynamic. Major changes in key structures and relationships within the health system (e.g., the recent health reform legislation) can impact who the decision makers are, what decisions they make, and how decisions are translated into action. ACOs, integrated health care delivery organizations promoted by federal healthcare reform, will have responsibility for the health of populations, as Kaiser Permanente, Group Health Cooperative, and other integrated managed care systems have had. They will need data on the health and risk factors of populations they serve to plan for the clinical, educational, and other resources needed to address their broad health needs, including for preventing and managing chronic diseases. State Health Benefit Exchanges, a key component of healthcare reform, will need good data on the health of populations, including their chronic diseases, that will seek health insurance coverage through them. The key overall design principle for a surveillance system is that it is a means to an end, and the dominant desired effect is to improve decision making by the system's many different users.

EMERGING SOURCES OF SURVEILLANCE DATA

As discussed in the previous chapter, surveillance data come from population-based surveys, investigational cohorts, registries, vital statistics and claims, other administrative data, and test results produced as a consequence of a healthcare encounter. Emerging experience with use of health information technologies (HITs) by both patients and providers suggests that in addition to current sources of information there will be expanding and potentially more efficient approaches to generating data for surveillance. Further, availability of new types of data such as patient care experiences and personal care preferences will expand the scope of what can be systematically monitored and examined. Expanded amounts of data with widening scope are increasingly being developed and generated by healthcare providers using HIT. Of particular interest is the potential, via the electronic health record (EHR), to economically and completely capture care events and processes and efficiently organize them into robust population- and condition-based registries.

In parallel, data are being recorded directly by patients, with or without initiation or direct support from providers and organized care systems. This direct patient involvement is being facilitated and promoted by a range of online personal health records. Systematic collection of information from patients in the form of individualized health assessments has been promoted by health systems, disease and care management entities, commercial wellness companies, and employers. Increasingly, this health assessment information is being commingled with other health data within large electronic data stores and used for population surveillance as well as performance assessment, predictive modeling, and care management.

The generation and sharing of personal health data by patients themselves is a growing health data phenomenon with potential implications for timely, robust, and relevant surveillance. This trend has its roots in the emergence of the Internet and has been amplified by the development and promotion of a range of new technical capabilities and appliances, commercial entities, and social relationships supporting the creation and wide sharing of highly personalized health data. A very recent contribution to surveillance of influenza is Google Flu (http://www.google.org/flutrends), which tracks Internet searches on flu-related topics. Comparing historical trends of the volume of such searches with CDC-produced trends of influenza cases shows a close correspondence; however, the volume of flu-related searches demonstrates the trend earlier than CDC data (Ginsburg, 2009). While a study by Ortiz et al. (2010) found that the estimates provided by Google Flu are not as reliable as the CDC national surveillance program, Valdivia and colleagues (2010) concluded that Google "could be a valuable tool for syndromic surveillance."

While the more traditional surveillance data resources have matured through use over decades, these newer candidate sources generally lack a comparable experience and evidence base. As use of HIT grows in coming

years, the potential is high that some if not all of these approaches may complement and extend the data foundations that presently exist.

Emerging Provider-Supported Data Sources for Surveillance: Registries, Electronic Health Records

The paper-based medical record of healthcare providers historically has been an uneven and often an inaccessible source of surveillance data. To access data, permission was needed from both the individual patient and the individual provider. Data collection required manual abstraction from paper records, and even when resources were available to abstract paper records, observations in the medical record lacked standardization and often legibility. Data useful for surveillance programs were frequently not recorded in standard formats or were not recorded at all, and population coverage was incomplete. Performing serial observations of patients and populations generally required repeat of intensive manual extraction steps.

The healthcare reform goal of universal coverage, along with broad promotion of health information technologies (especially the electronic medical record), may markedly increase the value of the medical record for disease surveillance. Near universal coverage of the population will create data that are closer to a virtual population census than is current available at any particular point in time. If constructed with population health management goals in mind, the electronic record can provide a more timely, standardized, and relatively inexpensive source of surveillance data.

While large registries provide useful data, they are potentially costly if not linked closely to care delivery, and furthermore, there are challenges identifying the denominators that they represent. When an electronic medical record is suitably designed, the same population analyses can be performed without duplicative data generation and handling. For example, Yeh and colleagues (2010) recently published incidence and case-fatality rate trends for acute myocardial infarction among the population covered by Kaiser Permanente of Northern California. Electronically available demographic data and electronic medical records essentially enabled a virtual population registry and made this analysis possible.

Identifying Patients for Registries

EHR data can be used to identify potential registry patients rather than relying on healthcare providers to recognize and enroll eligible individuals. Investigators can use the EHR to generate lists and prospectively register patients, or to identify potentially eligible patients during healthcare visits. This provides a reminder to clinicians to assess eligibility status and enroll eligible patients. To ensure that patients with a wide range of disease types and severity are included, the algorithms for prospective enrollees must identify individuals with any indication of CVD or COPD in their records. For example, one might include all patients with the diagnosis of angina, even knowing that it is wrong much of the time. Similarly, one could include all patients being prescribed an inhaled COPD medication, knowing that these are frequently used in patients with acute reactive airways disease (such as asthma) as well as COPD. The healthcare provider can then select from this group and enroll those patients who have the diseases of interest.

Stand-alone registries are useful tools for capturing patient-specific data for individuals with selected conditions; however, they have several shortcomings. These shortcomings include possible bias related to which patients are enrolled, missed subsequent data on patients, limited ability to investigate secondary questions, and reluctance of personnel to register patients—particularly on busy days. Envisioning dynamic linkage between EHRs and registries could overcome many of these concerns. Fewer biases in enrollment will exist because most practices and hospitals with EHRs use them for all patients. Investigators can indentify and utilize data for individuals with a condition(s) of interest, provided that reliable data are contained in the EHR. Moreover, data collection is likely to be more complete because the clinicians and the clinical systems collecting and reporting data are doing so for their own practices, not for an extraneous registry.

Challenges in Using EHR Data to Form Registries for Surveillance

Several challenges will need to be addressed in order to more fully use the EHR and associated registries for surveillance. First, EHRs are currently used in only a minority of U.S. hospitals and practices. The *American Recovery and Reinvestment Act of 2009* (ARRA)[3] and the *Health Information Technology for Economic and Clinical Health Act* (HITECH)[4] are providing financial incentives to promote the adoption and meaningful use of EHRs. The proportion of physician practices and hospitals using EHRs is expected to increase in the next decade, creating a growing opportunity for surveillance of chronic disease.

Patients with significant barriers to care will likely be underrepresented in EHRs. This problem may be resolved if national and state-level healthcare reform provides more Americans with health insurance and if other access barriers (such as health professions shortages and cultural barriers) are addressed. Healthcare providers only collect and record data needed to deliver care. This may not include data necessary for effective surveillance of cardiovascular disease (CVD) or chronic obstructive pulmonary disease (COPD). For example, although vital signs (e.g., blood pressure, heart rate, weight) are usually measured at all visits, capture of symptoms—especially the explicit absence of key symptoms—may be variable, with data preferentially recorded for patients who are symptomatic. Similarly, laboratory tests may be restricted to patients who are sick, have certain conditions, or are taking certain medications.

Sicker patients are likely to be overrepresented in EHRs. Since EHRs record healthcare delivery, there will likely be more data (more visits and more data per visit) for patients who are more acutely and chronically ill. Further, diagnoses are often coded and captured inexactly in EHRs. Some important data will be missing or difficult to analyze in most EHRs. For CVD and COPD, important descriptive and outcome data include symptoms and health-related quality of life which are not routinely recorded in EHRs by clinicians. When recorded, they are usually available only as non-standard free text. Free text (mostly in the form of dictated visit notes and letters) often contains selected, variable details in nonstandard formats that may not be quantifiable or amenable to combining and comparing data between providers or practices.

Despite these problems, EHRs can have an important role in CVD and COPD surveillance. EHRs reflect clinicians' interpretations and the real-world care that patients receive. They can be useful in CVD and COPD surveillance in two ways: identifying patients for registries, and providing outcome data. The expected growth of EHRs necessitates their inclusion in planning and development of any chronic disease surveillance system.

Implications of Multiple Providers and Multiple EHRs: The Role of Health Information Exchange

For a registry to be reliable and credible for surveillance, it will need to fully reflect the care received by a population. However, CVD and COPD registry patients will often present for cogent outcomes (e.g., heart attacks or exacerbations of COPD or sudden death) to multiple facilities and healthcare providers, each requiring linkage to the registry. EHRs from nearby healthcare facilities can be regularly queried to update cogent outcome data. According to Jha and colleagues (2009), a comprehensive electronic records system can be found in only 1.5 percent of hospitals in the United States. The authors reported that an additional 7.6 percent have a basic system (i.e., present in at least one clinical unit). Therefore, most hospitals and practices lack a comprehensive EHR that could automatically support outcome surveillance, which would also be hampered by lack of a universal identifier to link patients' data across healthcare institutions.

However, as noted above, the HITECH Act[5] is accelerating the speed at which practices and hospitals are implementing EHRs. To take advantage of the propagation of EHRs, various stakeholders from federal and state governments to local provider networks are creating and growing health information exchanges.

There is no movement in the United States to implement a single national EHR. Therefore, the federal Office of the National Coordinator for Health Information Technology (ONCHIT) is supporting the development of Regional Health Information Organizations (RHIOs). The Agency for Healthcare Research and Quality (AHRQ)

[3] See http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=111_cong_bills&docid=f:h1enr.pdf (accessed August 2, 2011).
[4] See http://www.hipaasurvivalguide.com/hitech-act-text.php (accessed August 2, 2011).
[5] Ibid.

has funded several statewide health information exchanges as examples of RHIOs and how they can be established and used to facilitate healthcare delivery by enhancing communication between providers (AHRQ, 2010). Adler-Milstein and colleagues (2011) found that most RHIOs that were in the planning phase in 2007 failed to become operational. Fifty-five RHIOs were operational, but data exchange was limited primarily to exchanging test results.

Combining data from multiple EHRs will require an EHR to embrace standards for patient identification (i.e., a core set of descriptive and demographic data that uniquely identifies a patient in multiple EHRs), content (i.e., the minimum set of core data an EHR must contain), coding (i.e., the terms it uses for conditions, tests, treatments, etc.), and messaging (i.e., the format in which patient data are exported from an EHR). Once established, health information exchanges and RHIOs could become rich resources for providing data for enrolling, describing, and following patients in registries.

Overcoming Barriers to the Use of the Electronic Medical Record as a Surveillance Tool: Protecting Patient Confidentiality and Data Sharing

In *Essential Features of a Surveillance System to Support the Prevention and Management of Heart Disease and Stroke*, Goff and colleagues (2007) recommended the development of mechanisms to "enable linkage between healthcare data systems, including the national surveillance programs (e.g., NAMCS, NHDS, and National Death Index), and electronic health records" (p. 3). They emphasized the critical importance of interoperability of national surveillance programs and electronic health records and the utilization of harmonized data standards. However, a formidable barrier to this goal is the lack of linkable unique health identifiers for individuals. Creative strategies are needed to facilitate this linkage while ensuring confidentiality (Goff et al., 2007).

In 1997, Lillard and Farmer described the advantages and challenges of linking Medicare and national survey data, and they concluded that the linkage of administrative and survey data could provide valuable information on health status, healthcare utilization, and socioeconomic characteristics. Currently, Medicare enrollment and claims data are linked with NCHS surveys including NHIS, NHANES, the Second Longitudinal Study of Aging, and the 2004 National Nursing Home Survey. Data are available for survey respondents who provided personal identification data that were successfully matched with Medicare administrative records. This effort was developed to "maximize the scientific value of the Center's population-based surveys" and "provides the opportunity to study changes in health status, healthcare utilization and expenditures in the elderly and disabled U.S. population" (NCHS, 2011). CMS data provided to NCHS includes Medicare benefit claims data (1991–2007), Medicare Part D data (2006 and 2007), and Chronic Condition Warehouse data (2005–2007). The linked NCHS-CMS Medicare data are restricted-use files that can be accessed by submitting an application to the NCHS Research Data Center.

Virtual Data Warehouse (VDW) Patient confidentiality must be ensured, and incentives for data owners (e.g., medical groups, health plans) to share their data must be created to facilitate use of the medical care data for surveillance. The HMO Research Network (HMORN)[6] is a collaborative network of 15 organizations that cover 11–15 million lives at any one time. The HMORN is addressing these confidentiality and data-sharing issues with the development of a Virtual Data Warehouse (VDW). The VDW was created as a mechanism to produce comparable data across sites for purposes of proposing and/or conducting research. The VDW is "virtual" in the sense that the raw ("real") data remain at the local sites; the VDW is not a multisite physical database at a centralized data coordinating center. At the core of the VDW are a series of standardized file definitions. Content areas and data elements that are commonly required for research studies are identified, and data dictionaries are created for each of the content areas. A common format for each of the elements—variable name, variable label, extended definition, code values, and value labels—is specified.

The Cardiovascular Research Network (CVRN), a network within the HMO Research Network (see Appendix A), conducts some studies with a different model in which de-identified individual level data are transferred from one or more sites to a central site for analysis. In a current effort funded by an NHLBI-sponsored Grand Opportunity grant to create a cardiovascular surveillance network within the CVRN, all 15 sites of the CVRN

[6] See http://www.hmoresearchnetwork.org/ (accessed August 2, 2011).

are sending up to 10 years of extensive data (2000–2009) from all the content areas of the VDW to a central site (Kaiser Permanente Northern California) for members who have been diagnosed with acute myocardial infarction, stroke, or heart failure. These data will be used to address research questions in the areas of comparative effectiveness and health disparities.

Local site programmers have mapped the data elements from their own legacy data systems onto the standardized set of variable definitions, names, and codes, as well as onto standardized SAS file formats. This common structure of the VDW files enables a SAS analyst at one site to write a program to extract and/or analyze data at all participating sites. The program from one site is emailed to programmers at other sites to run against their own VDW files. The resultant de-identified data are transferred to the analytic site via a secure encrypted website. Because the VDW maintains a history on past members, the number of people in the data base is much larger than the current membership. For example, HealthPartners in Minnesota actively covers about 700,000 lives, but it has 3 million individuals in the VDW. As of 2010, the standardized content areas developed include enrollment, demographics, utilization, diagnosis, procedures, tumor, pharmacy, census, provider specialty, vital signs, deaths, and laboratory data. Another example of a VDW is the development of the California Virtual Laboratory for Population-Level Analytics, which will integrate population health data (specifically, the California Health Interview Survey) with EHR data from participating healthcare delivery systems through a federated data-sharing system that pulls in key variables for specific analyses but allows the majority of data to remain at its source rather than being transferred en masse to a physical repository.

Veterans Health Administration (VHA) The VHA is the largest integrated healthcare system in the United States, comprising 153 VA hospitals, more than 750 community-based outpatient clinics, and 260 Vet Centers. The VHA-wide electronic health record is a notable data resource for disease surveillance, and a current initiative involves migration of their Computerized Patient Record System (CPRS) to a modern, web-based electronic health record (Department of Veterans Affairs, Strategic Plan Refresh: FY 2011–2015). Healthcare system data from the VHA has been cited for its potential usefulness as part of a national chronic disease surveillance system (Saran et al., 2010), and the public domain software developed and used by VHA to establish EHRs has been recognized as a model for promoting the use of EHRs in the ambulatory and impatient setting (Bufalino et al., 2011).

The VHA conducts numerous chronic disease surveillance activities, including those focused on diabetes, COPD, and CVD. The VHA collects, analyzes, and reports data on individuals with diabetes, including diagnoses, comorbidities, medications, healthcare utilization, and clinical outcomes. For COPD, outcome measures such as admissions and ICU stays, risk-adjusted standardized mortality ratios, risk-adjusted length of stay, and 30-day readmission rates are collected. The VHA has also been a leader in remote pacemaker monitoring, and established a National Implantable Cardioverter Defibrillator (ICD) Center in 2003 (Varosy, 2010). Another VHA initiative, The Clinical Assessment, Reporting, and Tracking (CART) system, is described as an example of national, proactive point-of-care device surveillance. The CART system is "a clinical application embedded in the electronic health record that enables clinicians to document any unexpected problems with devices used in cardiac procedures as part of regular care documentation and is linked to longitudinal outcomes data" (Rumsfeld and Peterson, 2010). CART involves standardized data capture across all the VA cardiac catheterization laboratories, is integrated within the CPRS, and the core data elements conform to the American College of Cardiology's National Cardiovascular Data Registry. This system enables integration of data collection into the transaction of care, patient safety monitoring, device surveillance, and health services research (Varosy, 2010). The surveillance activities coordinated by the VHA may provide valuable information and lessons in the development of a framework for national cardiovascular and chronic lung disease surveillance.

Vaccine Safety Datalink (VSD) The VSD also uses standardized medical record data for surveillance (http://www.cdc.gov/vaccinesafety/activities/vsd.html). The VSD is a collaboration among the Centers for Disease Control and Prevention, America's Health Insurance Plans, and eight HMOs to monitor and assess the safety of childhood and adult vaccines. The eight participating HMOs have created identical data sets of all vaccine exposures and all medically treated illnesses, as well as demographic information (birth, gender, race, residence, primary language, and need for interpreter). The VSD supported nearly 30 projects in 2009, including the following:

- H1N1 Vaccine Safety in Pregnant Women
- Safety of the Yellow Fever Vaccine Among Children and Adults
- Henoch Schonlein Purpura and Meningococcal Vaccine
- Rapid Cycle Assessment of Adolescent Tetanus, Diphtheria & Pertussis (TDaP)
- Influenza Vaccine Safety in Pregnant Women
- Rapid Cycle Analysis of Meningococcal Conjugate Vaccine Safety
- Wheezing and Lower Respiratory Disease (WLRD) Multisite Study
- Rapid Cycle Analysis of Pentavalent Rotavirus (RotaTeq) Vaccine Safety
- Assessment of the Burden of Rotavirus Disease and Impact of Rotavirus Vaccination Among Children < 5 Years of Age
- Safety of TIV in Children Aged 24 to 59 Months
- Injections Site and Local Reactions to the Fifth Diphtheria, Tetanus & Pertussis (DTaP) Vaccination
- Does Influenza Vaccination in Children with Sickle Cell Disease Result in an Increased Risk for Fever and/or Pain Crises?

Data from Patients: Potential Use in Surveillance

Approximately 80 percent of Americans use the Internet, more than half of adults regularly go online, and a substantial part of this activity is health related according to data from the Internet and American Life Project of the Pew Research Center.[7] Between 2006 and 2008, the proportion of individuals who responded that they or someone they know had been helped by medical advice found online grew from one-quarter to nearly one-half. In addition to seeking and consuming information, a growing proportion of these users are also sharing and contributing data and information. Over one-third of Internet users share images such as photos, and about 20 percent of cancer patients use social networking sites to share and obtain health information.

This pattern of patient information seeking and sharing is also reflected by infrastructure design and implementation. For example, among regional and state initiatives to create RHIOs, a rapidly growing proportion are developing capabilities for patients to both view their personal health information directly and to contribute information on their health status (eHealth Initiative, 2010).

Health Risk Appraisals

Efforts to systematically collect information from patients in the form of individualized health assessments have been promoted by many organized care delivery organizations, including health systems, disease and care management entities, and commercial wellness companies. Data from the 2004 National Worksite Health Promotion Survey demonstrated that 45.8 percent of work sites with more than 750 employees used health risk appraisals (Linnan et al., 2008). Among firms that offer health benefits to their workers, 11 percent give their employees the option of completing an HRA, about a fifth of which also offer financial incentives to encourage workers to complete them (Kaiser Family Foundation and Health Research & Educational Trust, 2011).

The term health risk assessment is sometimes used interchangeably with health risk appraisal. However, Anderson and Staufacker (1996) state that the term health risk appraisal (HRA) "formally refers to the instrument whereas health risk assessment refers to the overall process (e.g., orientation, screening, interpretation, counseling) in which the HRA instrument is used." HRAs are used to develop health profiles, estimate future risks of adverse health outcomes, and provide information to reduce risks. Employers seeking to understand and address the health needs of their workforce have contributed to the use of proactive health surveys and personalized health appraisals. Furthermore, these employers have used survey tools as a mechanism to better create awareness and engagement among their employees. Health appraisal information is increasingly being commingled with other

[7] See http://www.pewinternet.org/Trend-Data/Whos-Online.aspx (accessed August 2, 2011); http://www.pewinternet.org/Trend-Data/Whos-Online.aspx (accessed August 2, 2011).

health data within large electronic data stores and used for prioritization of population-based interventions as well as performance assessment, predictive modeling, and care management.

HRAs are widely used in workforce wellness programs and have the potential to provide important information for chronic disease surveillance. According to the CDC, however, how HRAs impact health risk behavior or related health indicators, such as body composition and cholesterol levels, is not well understood (CDC, 2011c).

Personal Health Records and Patient Access to the EHR

With federal incentives for the expanded use of HIT in clinical practices and hospitals as part of the *American Recovery and Reinvestment Act of 2009*, there is also a growing use of patient-facing aspects of these primarily clinically directed technologies. In addition to support for providers having complete and reliable access to information about their patients, priority is being directed at patient empowerment by HIT so that patients can take a more active role in managing their health. The initial phases of the Meaningful Use HIT incentive program included specific inducements for both direct provision of health information and health record access by providers to patients. It also promoted the development of capabilities to capture patient-identified preferences, experiences, and survey responses as a regular component of routine HIT supported care delivery.

Recording of data by patients in health IT systems is being further facilitated by a range of online personal health records. These may be provided by health insurers, integrated delivery systems, commercial providers of health information tools and support, and freestanding personal health records. Examples of this latter group include HealthVault from Microsoft,[8] GoogleHealth,[9] and Dossia.[10] Patients are increasingly sharing their personal care experiences as well as impressions of individual physicians and other aspects of care delivery through online consumer reviews of individual physician practices.

Sharing of Data Among Patients

Timely access to personally relevant information has been a driving force for patients to form, join, and share experiences and data within a range of organizations independent from historically defined public health, healthcare delivery, and health research entities. These associations often arise among individuals with a specific health condition or disease and have a wide range of organizational structures. They range from formally organized not-for-profit and even commercial corporations imbued with substantial information and knowledge resources to ad hoc and spontaneous patient networks for communication and experience sharing that coalesce via newer Internet social networking tools such as Facebook and Twitter. A few examples of a rapidly expanding array of patient-oriented communities and companies include:

- The Association of Cancer Online Resources (ACOR). "ACOR offers access to 159 mailing lists that provide support, information, and community to everyone affected by cancer and related disorders" (http://www.acor.org/, accessed December 1, 2010). Through supported communities and networks, patients share care-related information such as treatment responses as well as drug adverse effects that they have encountered.
- The Chordoma Foundation (http://www.chordomafoundation.org/) links patients, families, clinicians, and researchers involved in the treatment of this rare cancer, providing pooling of clinical data, individual treatment responses, and researcher interests.
- PatientsLikeMe (http://www.patientslikeme.com/) is a privately owned online company supporting extensive communities of individuals with conditions like amyotrophic lateral sclerosis (ALS) and multiple sclerosis (MS) by providing online self-report tools and population-based reporting to monitor disease course and treatment responses.

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[8] See http://www.healthvault.com/personal/index.aspx (accessed August 2, 2011).

[9] See https://www.google.com/accounts/ServiceLogin?service=health&nui=1&continue=https://health.google.com/health/p/&followup=https://health.google.com/health/p/&rm=hide (accessed August 2, 2011).

[10] See http://www.dossia.org/ (accessed August 2, 2011).

Social Networking Registries

A new tool that has the potential to modify the future of surveillance and population-based research is the development of registries that integrate social networking (i.e., Facebook or similar sites) to recruit and retain subjects. Two forms of registries that are currently being used are population-based registries of a general population and disease-specific registries. Examples of population-based registries are ones recruiting in Kentucky and Illinois. As of December 2010, the Illinois Women's Health Registry (https://whr.northwestern.edu/) had more than 5,000 subjects, and the Kentucky Women's Health Registry had over 13,000 subjects (https://www.mc.uky.edu/kyhealthregistry/).

The purpose of the Illinois Women's Health Registry is to provide a research and education tool that advances scientific knowledge of sex- and gender-based differences in health and disease. It is a confidential 30-minute health and lifestyle survey for female residents of Illinois over age 18 and includes questions regarding health, environment, health-related behaviors, symptoms, and illnesses or conditions that a participant may have now or has had in the past. By enrolling in the registry, women throughout the state are provided with information and access to clinical research studies that they may be eligible for based on their self-reported health information. The registry not only serves as a platform for recruitment into pivotal research studies but also represents the beginning of a statewide database that enables researchers to examine the collective de-identified health information provided by women living in Illinois (Bristol-Gould et al., 2010).

The Kentucky Women's Health Registry is similar with regard to its mission and scope, and its data have already appeared in a peer-reviewed publication (Coker et al., 2009). Both of these registries have cross-sectional as well as longitudinal components and can be used to provide data for analytic studies and study subjects for more in-depth studies.

An advantage of registries linked to social networking capabilities is that one has the potential to follow people easily as they move around the country and even internationally. For those registries linked to social networking systems, their voluntary and non-randomized participation makes generalizing the data obtained from them challenging. For example, participants in the Kentucky Women's Health Registry are more highly educated, with a much lower smoking prevalence than among the general population of women in Kentucky (Coker et al., 2009).

Privacy concerns are raised by such registries, particularly those linked to social networking systems or commercial enterprises. As social networking makes tracking individuals easier for research, there are concerns about the potential to identify individuals who have shared medical information with an expectation of privacy. Similarly, commercial organizations, such as health promotion firms that contract with employers or health insurers, are expected to protect the privacy of individuals and not share it with sponsoring entities.

Implications of Patient-Generated Data: Potential, But Uncertainty

The generation and sharing of patient information via the Internet and associated social media tools is increasingly common, despite substantial concerns about the protection of patient and provider confidentiality and the ability to reliably use and leverage these data as more than chaotic collections of independent anecdotes. As noted, patients are forming, refining, and increasingly relying on these sources for individual and family guidance. Patients are extensively sharing personal clinical findings, care experiences, and perceived impacts and outcomes of the care they are receiving. As these data are evolving in form, scope, and quality, potential integration into surveillance activities systems can be a focus of experimentation and learning, with one of the largest challenges being the lack of confidence that patterns of health among people who share medical information is similar to those who choose not to share. The growing abundance of data at a highly personal level provides opportunity for further exploration and development as part of a robust surveillance framework.

The current picture of CVD and COPD surveillance in the United States presents a wide range of disparate data courses, often driven by different needs. The creation of a surveillance system built upon current data collection approaches will need to balance a number of challenges, not least of all the tension between cost and granularity, and the differing needs of the different user constituencies of data. The growth of electronic records, as well as emerging data capture, mining, and search technologies, also pose major opportunities and challenges.

Developing Systems

All-Payer Claims Databases

A number of states have begun developing all-payer claims databases (APCDs), which combine data from all the payers within a state. These APCDs may have a wide variety of claims data (medical, dental, pharmacy) from both public and private payers. Such databases are established by state legislative mandate, although some states are pursuing the creation of such databases on a voluntary basis. An article by Love and colleagues (2010) reported that 12 states had passed APCD legislation at the time of the article and that there were 11 existing APCDs, with an additional 2 expected by the end of 2010. There is significant variation in polices regarding release of data, with regulations established by each individual state with a legislative mandate. Because APCDs are based on claims data, they are subject to the same limitations as discussed earlier.

Public Health Information Network

The Public Health Information Network (PHIN) is an initiative undertaken by the CDC that is designed to improve public health capacity to use and exchange information electronically. The PHIN, first funded in 2004, originally focused on information systems for improving public health preparedness and response. Today, however, the PHIN strategic plan describes the mission of the PHIN as developing "shared policies, standards, practices, and services that facilitate efficient public health information access, exchange, use, and collaboration, among public health agencies and with their clinical and other partners" (CDC, 2011e).

According to its strategic plan, the PHIN has faced significant challenges, including lack of clear direction, disjointed program planning, alienation of state and local users, costs, and lack of necessary technical capability in many public health settings. To address these issues, the PHIN updated its vision, mission, and goals. The new goals are:

1. Provide leadership in the selection and implementation of shared policies, standards, practices, and services for nationwide public health information exchange.
2. Define, advocate for, and support public health needs and roles in national health information technology and exchange initiatives.
3. Perform key public health information exchange and standards management roles.

The PHIN "will harmonize with and become integral to, the Nationwide Health Information Network, creating the easy-to-find 'on- and off-ramps' that enable public health information management systems to use the Nationwide Health Information Network superhighway" (CDC, 2011a). Among PHIN strategies for achieving its goals and objectives are those focused on:

- Establishing well-functioning governance structures and processes.
- Defining and maintaining an architectural framework for public health information exchange.
- Fostering development of information-sharing processes and agreements.
- Harmonizing PHIN as a component of the Nationwide Health Information Network.
- Developing, publishing, and maintaining public health information exchange specifications.
- Establishing PHIN certification for public health information technologies.
- Participating in national standards and implementation processes.
- Providing "data hub" services for national data sets.
- Providing technical services aimed at assisting public health agencies collaborate in standardization and interoperability processes.

BioSense One component of the PHIN is BioSense, which facilitates "the sharing of automated detection and visualization algorithms and approaches by promoting national standards and specifications developed by such

initiatives as the PHIN" (Loonsk, 2004). BioSense was established by the CDC in response to the *Public Health Security and Bioterrorism Preparedness and Response Act of 2002,* which mandated development of a national public health surveillance system to detect potential bioterrorism-related illness. In 2010, BioSense was redesigned in order to "provide nationwide and regional situational awareness for all-hazard health-related threats (beyond bioterrorism) and to support national, state, and local responses to those threats" (CDC, 2011b).

BioSense is national in scope and focuses on obtaining, analyzing, and reporting data on bioterrorism-related illness, as well as information on situational awareness, and public health response. According to CDC, there are over 800 registered users and the system connects with over 500 hospitals. The system receives data from over 1,000 Department of Defense and Veterans Affairs hospitals and healthcare facilities as well as laboratory data from LabCorp and Relay Health (CDC, 2011d).

National Electronic Disease Surveillance System (NEDSS) The National Electronic Disease Surveillance System is another component of the Public Health Information Network. It is designed to promote the use of data and information systems standards to advance the development of efficient, integrated, and interoperable surveillance systems at the federal, state, and local levels (NEDSS Working Group, 2001). NEDSS is a web-based system designed to enable the secure transfer of public health, laboratory, and clinical data from healthcare providers to public health departments. The broad initiative is intended to facilitate the rapid detection of outbreaks, facilitate electronic transfer of information, reduce provider burden in the provision of information, and enhance the timeliness and quality of information provided (CDC, 2011e).

The vision of NEDSS is "to have integrated surveillance systems that can transfer appropriate public health, laboratory, and clinical data efficiently and securely over the Internet. Once implemented, NEDSS is expected to improve the nation's ability to identify and track emerging infectious diseases and potential bioterrorism attacks as well as to investigate outbreaks and monitor disease trends" (CDC, 2011e). The mission of NEDSS is to serve the following needs at the local, state, and national levels:

- Monitor and assess disease trends
- Guide prevention and intervention programs
- Inform public health policy and policy makers
- Identify issues needing public health research
- Provide information for community and program planning
- Protect confidentiality while providing information to those who need to know

The principles of the NEDSS design are based on utilization of industry standards, reliance on off-the-shelf software, Internet-based secure transmission of data, a common look and feel of systems, common reporting requirements, and no requirement to use specific software. NEDSS is intended to integrate and replace several current CDC surveillance systems, which are limited by various issues, such as the use of multiple incompatible disease specific systems, incomplete and delayed data, and lack of state-of-the-art technology (CDC, 2011e).

Results from a 2007 assessment of the use of various electronic surveillance systems showed that public health agencies in 16 states (32 percent) reported using the NEDSS Base System as their general communicable disease electronic surveillance system. The remaining 34 states (68 percent) reported using some combination of commercial, CDC, or state-developed electronic surveillance systems to meet their needs. Among the 50 states, 39 (78 percent) reported that at least one aspect of their surveillance system was under development or planned (CDC, 2009). These results demonstrated substantial variation in state electronic disease surveillance systems, although there was a strong commitment to achieving interoperability among systems within states. However, "as interoperability becomes the standard for electronic data sharing, more states will face customization costs and increasing demand for IT personnel in the workforce" (CDC, 2009).

Currently, PHIN, BioSense, and NEDSS are in various stages of development. As is the case with using EHRs for surveillance, a major challenge relates to the relatively small number of public health institutions that have effective, efficient, and interoperable health information technologies. Furthermore, it is likely that much of the data collected by the PHIN and BioSense are not relevant to CVD and COPD surveillance and much of the

data that are relevant are not likely to be collected in these systems. However, PHIN, BioSense, and NEDSS are interesting models for information exchange that could provide lessons in many issues related to the development of a nationwide surveillance system for cardiovascular and chronic lung disease. Such lessons could include those related to technical issues, challenges of integrating multiple stakeholder interests and systems, and collecting and providing information to users at multiple levels.

Sentinel Initiative

In response to the passage of the *Food and Drug Administration Amendments Act* (FDAAA), which mandated that the U.S. Food and Drug Administration (FDA) enhance their ability to monitor the safety of drugs after they reach the market, the FDA launched its Sentinel Initiative in May 2008. The goal of the initiative is to create a national, integrated, electronic system for monitoring medical product safety that will complement existing systems that track reports of adverse events linked to the use of regulated products. The Sentinel System, which will involve collaboration with a wide array of organizations (e.g., academic medical centers, healthcare systems, and health insurance companies), will be developed and implemented in stages and will draw on the capabilities of existing data systems such as electronic health record systems and medical claims databases. The electronic data used in this process will remain in existing, secure environments as a distributed system rather than being consolidated in one database. Within the distributed system, a coordinating center will receive and process FDA-generated safety questions (FDA, 2010).

The Sentinel System vision involves two main components: active surveillance via a distributed system, and expansion of FDA's current safety surveillance capabilities.

The active surveillance environment will prioritize safety questions that emerge from premarket or postmarket safety data sources such as clinical trial data and spontaneous adverse event reports. The questions will be submitted to the coordinating center for evaluation where the data partners will securely access their databases to evaluate the question and compile HIPAA-compliant results that will ultimately be forwarded to FDA.

Two pilot programs, Mini-Sentinel pilot and the Federal Partners' Collaboration, are helping shape the Sentinel System. Launched at the end of 2009, the Mini-Sentinel will enable FDA to query privately held electronic healthcare data (including administrative claims and clinical data) representing approximately 60 million patients. The Federal Partners' Collaboration, which includes the Centers for Medicare & Medicaid Services (CMS), the Veterans Health Administration at the Department of Veterans Affairs (VA), and the Department of Defense (DOD), will enable FDA to query federally held electronic healthcare data, including administrative and claims data and data from electronic health record systems. These pilot projects will provide information about the complex needs of an active surveillance system and will encourage a design that addresses technological, methodological, legal, and operational challenges of the Sentinel System (FDA, 2010).

The emerging FDA Sentinel System provides a rich source of information for those charged with developing a national surveillance system for cardiovascular and chronic lung diseases. While the FDA system is dependent on emerging health information technology which, as yet, is not widespread among healthcare institutions, the challenges faced and solutions developed will be of great use in creating a surveillance system that provides necessary information on prevention, treatment, and outcomes for CVD and COPD.

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7

Using Surveillance Data for Action

The committee concluded that a coordinated surveillance system is needed to integrate and expand existing information across the multiple levels of decision making in order to generate actionable timely knowledge for stakeholders at the local, state or regional, and national levels. A robust surveillance system will help to monitor, evaluate, and improve policies, programs, and services; better direct the placement of resources; and provide a stronger basis for advocacy and education and a benchmark for clinicians. During its deliberations, the committee discussed whether the framework the committee was charged with developing should focus on chronic diseases in general or whether it should be oriented more specifically to cardiovascular and chronic lung diseases. The charge to the committee mentions both. The committee concluded that the focus, as stated in the charge, should be "primarily on cardiovascular and chronic lung disease." An enlarged focus on chronic diseases would require an expanded committee, a lengthier study process, and additional resources that were not available. However, the committee resolved to work to ensure that the framework and infrastructure it recommends will, to the extent possible, be applicable to other chronic diseases.

The committee's rationale for a nationwide cardiovascular and chronic lung diseases surveillance system is based on the recognition of major gaps in current monitoring approaches and on new opportunities provided by emerging technologies, data collection mechanisms, and healthcare reform. Rather than construct an entirely new surveillance system, however, the committee concluded that existing surveillance data collection efforts and cohort studies can and should be strengthened and integrated to provide the necessary surveillance information. In terms of gaps, chronic disease trends are currently monitored by different stakeholders through an incomplete patchwork of surveys (some standardized and many non-standardized), registries, cohort studies, and mortality vital statistics (German et al., 2001; Goff et al., 2007). Although national surveys remain a critically important source of information on behaviors, clinical preventive service use, and prevalence of diagnosed and undiagnosed conditions, how trends vary across localities is poorly understood. Furthermore, local institutions lack technical guidance, useful tools, and adequate resources to effectively monitor these outcomes in their own jurisdictions and patient populations. Detailed patient data on disease incidence, severity, treatment practices, and outcomes are gathered in many healthcare institutions and by most insurance companies without standardization or the means to disseminate more broadly or even compare the patterns and trends of their patient populations with benchmarks for the larger population. Key data sources such as Medicare and Medicaid are not easily accessed at the state and local levels, where targeted change is most likely to occur, nor are they readily linkable to other data sources. Underlying these weaknesses is the lack of national coordination and leadership for these disparate efforts.

In terms of opportunity, standardized initiatives to improve quality of care, the rapid expansion of electronic health record (EHR) systems and patient registries, and the recent passage of the *Patient Protection and Affordable Care Act* have all opened new avenues for the systematic collection, analysis, and dissemination of information on the incidence and severity of chronic disease in populations under care (Chassin et al., 2010). National leadership has been at the forefront of these recent developments, an example of the valuable opportunities that exist to extend that leadership to completing and unifying the fragmented components of chronic disease surveillance identified in this report.

Successful implementation of a framework for national surveillance of cardiovascular and chronic lung diseases requires a mechanism to coordinate, monitor, and support the multiple data collection systems that contribute to the surveillance system. Furthermore, the system must provide ways to ensure that the elements collected can evolve in step with new knowledge about emerging risk factors, advancing technologies, and new understanding of the basis for disease.

Given that the mission of the Department of Health and Human Services (HHS) is to protect the health and provide essential services to Americans,[1] that HHS is already responsible for the funding and conduct of numerous surveillance efforts, and that it is in a position to bring together stakeholders from both the public and private sectors as well as from multiple geographic levels, the committee believes HHS is in the best position to lead the development and implementation of the recommended framework and system. Because the recommended framework is based upon existing data collection approaches, it is crucial that those organizations responsible for the conduct of those approaches be involved in determining the ways to use and integrate existing approaches. It should be recognized, however, that resources are rarely available to support all the desires of each of the stakeholders. As discussed in Chapter 6, trade-offs will have to be made in terms of what data are to be collected and the mechanisms for doing so. For example, cost constraints may result in sampling rather than a full population assessment or the use of self-report rather than biological examinations.

It is critical that those who represent their organizations or agencies on the committee have expertise in the prevention, diagnosis, treatment, and surveillance of CVD or COPD or have access to such expertise as they engage in their deliberations in order to address the problems and issues confronting them as they work to integrate and enhance surveillance for these conditions. For example, as discussed in Chapter 3, a number of difficult issues regarding collection of data for the surveillance of COPD remain to be resolved, and it is anticipated that the working group will play a major role in such resolution. The committee believes strongly that federal agencies should collaborate with the many state and local public agencies and national and state-level, nongovernmental organizations that conduct components of the proposed system.

The use of a coordinating body, as the committee recommends below, is in line with the approach taken by Canada in its developing Canadian Chronic Disease Surveillance System[2] (CCDSS), which integrates a network of provincial and territorial surveillance systems. The CCDSS began with diabetes surveillance and, in 2009, expanded the system to track information on the incidence and prevalence of diagnosed hypertension. The intent is to expand the system over time to include surveillance of other chronic diseases. The Canadian system is guided by a Task Group on Surveillance of Chronic Disease and Injury. The membership of the Task Force is composed entirely of government agencies, however, and the committee strongly believes that developing an effective system for the United States requires the involvement of both public- and private-sector stakeholders.

Recommendation 1

The committee recommends that the Secretary of HHS establish and provide adequate resources for a standing national working group to oversee and coordinate cardiovascular and chronic pulmonary disease surveillance activity. This working group should include representatives from HHS (CDC, NIH, AHRQ, CMS, IHS, ONCHIT, FDA), other relevant federal agencies (e.g., VA and DOD), and tribal, state, and local public health agencies, as well as nongovernmental organizations with relevant roles in surveillance.

[1] See http://govinfo.library.unt.edu/npr/library/status/mission/mhhs.htm (accessed August 2, 2011).

[2] See http://www.phac-aspc.gc.ca/cd-mc/cvd-mcv/ccdss-snsmc-2010/2-1-eng.php (accessed August 2, 2011).

BUILDING A FRAMEWORK

Effectiveness of a surveillance system depends on several factors. These factors are the quality of the data; the ongoing, systematic collection, analysis, and interpretation of the data; the ongoing use of the results to plan and implement prevention and control strategies; and the regular feedback from the end users to those organizing surveillance systems so that a dynamic system can evolve in a continuous manner. A surveillance system for cardiovascular and chronic lung diseases must provide data that can be used to understand the continuum of prevention, disease progression, treatment, and outcomes, and can be flexible enough to respond to new challenges and opportunities. Data are needed that can provide information on

- Incidence and prevalence of relevant conditions over time;
- Primary prevention, including both elimination of exposures in the physical and social environments that cause these diseases and reducing behavioral, clinical, and other risk factors (e.g., physical inactivity, poor diets, and smoking);
- Secondary prevention efforts (i.e., early detection and intervention);
- Tertiary prevention (i.e., management of symptomatic disease);
- Health outcomes, including quality of life;
- Costs, including both the direct medical costs and the indirect costs of lost productivity, earnings, and social burden; and
- Disparities in these factors by race or ethnicity, geographic region, and socioeconomic status. Furthermore, the system must be flexible enough to respond to new challenges and opportunities.

Recommendation 2

The committee recommends that the national working group place priorities for surveillance on data systems that can overtly:

- **Track progress on nationally recognized goals and indicators regarding cardiovascular disease and chronic pulmonary disease incidence, prevalence, and prevention (e.g., Healthy People);**
- **Evaluate and inform national, state, and local efforts to control, reduce, and prevent these chronic diseases;**
- **Enable effective public health actions and policies;**
- **Improve treatment outcomes;**
- **Monitor and enhance quality of life; and**
- **Reduce disparities in risk and burden of these diseases.**

Setting the Foundation

As noted in prior sections, the sources and types of data potentially applicable to surveillance can be cataloged and systematically combined to provide a diverse and rich resource. These resources can be used to generate information and knowledge about chronic diseases that are useful in tracking prevalence, guiding public health and prevention efforts, informing efforts to manage and treat the diseases, and developing policies that address disparities. Similarly, the users of surveillance data can be identified and assisted by prioritizing their data requirements, organizing data into measures and indicators that inform decisions, and developing dissemination strategies to make the data accessible and useful for them.

The data resources and the uses and users of those data are critical to refining the requirements for a surveillance framework. However, the data needed and the decisions to be made are complex, evolving, and interdependent. This requires the conceptual backbone of a framework that leverages knowledge we already have and provides durability and adaptability going forward.

Many chronic cardiovascular and lung conditions share common risk factors and follow a broadly similar natural history within patients and populations, which enabled the committee to adapt for its purposes a conceptual

framework for cancer surveillance developed by Wingo and colleagues (2005) and illustrated in Figure 7-1. The trajectory of a chronic disease usually begins at younger ages with a period of apparent good health, often with underlying risk factors present. Some risk factors may be genetic or congenital, others may be behavioral, and others may be found in the person's social or physical environment. The risk factors may be ignored for a time, but eventually they are likely to lead to clinical signs or symptoms that motivate the person to consult health professionals. It is critical in the new surveillance system to collect data on these risk factors in order to identify precursors prior to or at the very earliest states of disease.

Alternatively, these early manifestations may be detected through screening. The person may then transition through diagnosis to treatment and an objectively changed stage of life. Once diagnosed, progression of symptoms may be controlled or may proceed at variable rates as individuals live with a chronic condition and its management. Either as a consequence of the initial condition or due to other intercurrent and complicating events, patients also experience other conditions and, eventually, the end of life. The stages of health (with risk factors), diagnosis, treatment, living with a chronic condition, and end of life are predictable in both likely occurrence and sequence.

Incorporating the logic and practices of primary, secondary, and tertiary prevention completes the crux of the framework. Prevention involves actions aimed at preventing or reducing the occurrence of a condition or minimizing the effects of a condition. Primary prevention is concerned with deterring the occurrence of disease in a population through strategies aimed at disease risk factors. Secondary prevention promotes the early detection of disease so that prompt treatment can be given in order to prevent further deterioration and early death. Screening services are major secondary prevention strategies. Tertiary prevention focuses on disease treatment and management to reduce the impact of disease (Last, 2001; Modeste, 1996).

Decision makers at all levels must recognize that prevention is relevant at all stages of a chronic health condition. Such recognition will aid in ensuring that policy, system design, and practice align to identify and deliver appropriate interventions throughout the course of a chronic condition.

Information about chronic conditions that evolve over the life course should include data on the timing and appropriateness of preventive and therapeutic interventions; identify patterns of incidence and prevalence;

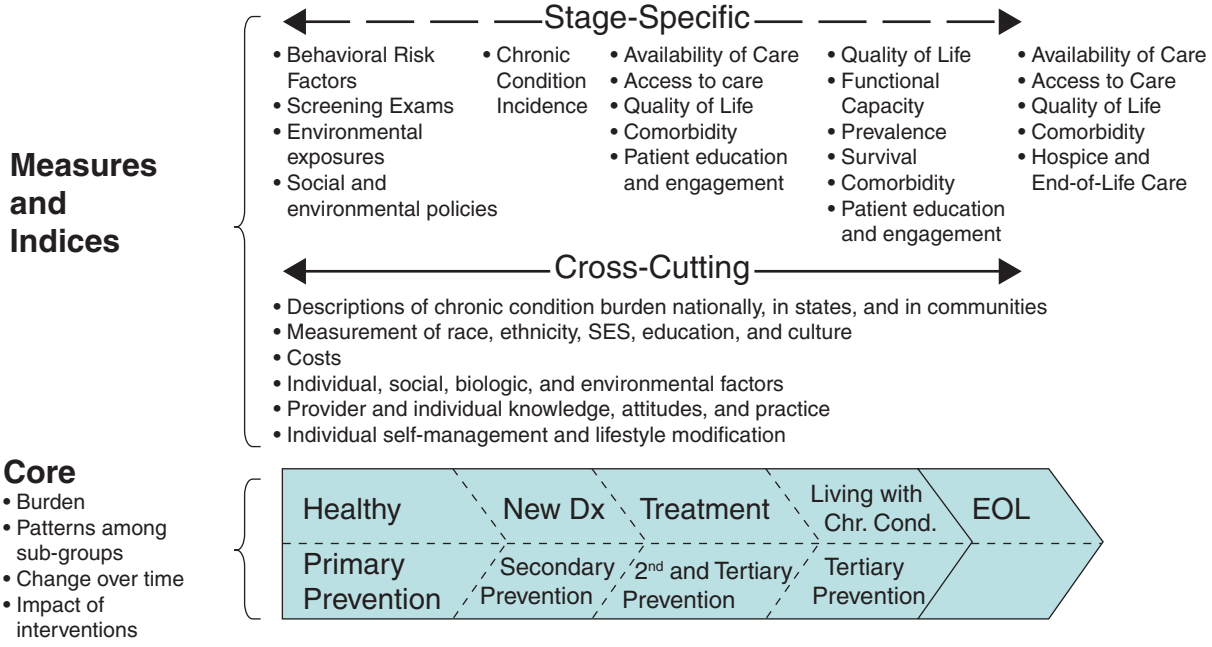

FIGURE 7-1 Framework for a national surveillance system for cardiovascular and chronic lung diseases.
SOURCE: Adapted from Wingo et al., 2005.

hypothesize about causation; track changes over time; and observe the impact of interventions on important health outcomes. Collecting and integrating data at each stage in the course of a chronic condition is important to a comprehensive surveillance system.

Measures and Indexes

Linking the information arising within the core of the framework to action occurs through a generation of measures and indexes. Within the core framework of progression of conditions and interventions over a life course, some measures and indexes will apply to specific stages of the condition sequence, while other measurements will apply to most if not all stages. Recognition and incorporation of both cross-cutting and stage-specific metrics is an important feature for fully supporting the range of decision makers. A full specification of a portfolio of measure and index definitions is beyond the scope of this report; however, examples of both cross-cutting and stage-specific measure concepts are included in Figure 7-1.

Recommendation 3

The committee recommends that HHS adopt the framework illustrated in Figure 7-1 as a guide for national surveillance of cardiovascular and chronic lung diseases.

The framework organizes data from traditional, evolving, and novel surveillance sources to reflect the development and progression of chronic conditions over a life course. The design also captures the impact of prevention as both a goal and an interventional intent. Information emerging from this core can be assembled into both cross-cutting and stage-specific metrics to inform the actions of decision makers in multiple roles and at the macro, meso, and micro levels of the health and healthcare systems. This general framework, while evolved specifically for chronic heart and lung diseases, is anticipated to be broadly applicable to other chronic health conditions, including the increasingly common occurrence of multiple chronic health conditions in the same individual.

Various data are needed to facilitate an effective surveillance system for cardiovascular disease and chronic lung disease. These data include information about incidence and prevalence of the conditions of interest as well as their risk factors, prevention efforts, treatments, and health outcomes. Chapter 4 describes the need to untangle the effects of environment, income, education, race, ethnicity, and genetics on cardiovascular disease (CVD) and chronic obstructive pulmonary disease (COPD) to foster the elimination of health disparities. Such efforts require more effective and efficient linkages of conventional surveillance data to these more contextually relevant data (e.g., socioeconomic status, birthplace, acculturation, geography, language, insurance, etc.).

Furthermore, an effective surveillance system must evolve to account for changing case definitions (e.g., those of myocardial infarction and COPD). It must also allow recognition of new disease entities and an understanding of how changes in public policy affect the disease being studied and how risk factors can have a major impact on incidence and prevalence of other diseases. For example, a reduction in heart disease deaths may lead to an increase in cancer prevalence as more individuals survive to older ages, when cancer becomes more common.

Incidence and prevalence of disease can be greatly affected by the presentation of patients into a node of the medical system. For instance, if a patient who suffers from chronic respiratory illness fails to seek medical care and hence does not receive a diagnosis of COPD, then it will be undercounted in survey data, which typically rely on questions such as “Did a doctor, nurse, or other health professional ever tell you that you have . . . ?” Similarly, patients who experience “silent” myocardial infarctions or who do not have cardiac enzymes drawn or electrocardiograms performed at the time of infarction will contribute to underreporting of the true incidence or prevalence of disease. Therefore it becomes essential to understand how a patient’s awareness of a condition, symptom, or disease can affect the seeking of medical care, and the apparent incidence or prevalence of disease as gathered by surveillance/reporting systems. Similarly, there are significant gender differences in the constellation of symptoms of cardiovascular disease for women as opposed to men. As awareness campaigns gain traction, women may seek more medical attention. This can lead to more diagnoses of CVD in women, and an apparent rise in incidence.

Cardiovascular and pulmonary diseases do not occur in isolation. Each exists on a backdrop of multiple other diseases whose risk factors, incidence, and prevalence are themselves changing. Because COPD contributes to an increased risk of myocardial infarction, it becomes increasingly imperative to consider the changing prevalence of COPD in surveillance of myocardial infarction. Similarly, the landscape of many risk factors for cardiovascular disease, diabetes, measures of glycemic control, hypertension, hypercholesterolemia, and other comorbities change over time. It is important to understand the fabric of change in which a disease and its risk factors are surveyed.

As discussed in Chapter 5, current surveillance efforts for CVD and COPD are incomplete. There are clear gaps in data collection of patient outcomes that are critical for surveillance. Functional capacity, quality of life, and patient engagement, and action measures are needed. Clear definitions and measurement techniques will need to be tested and implemented. Finally, a system is needed to overcome the many uncoordinated efforts that frequently produce inconsistent information (Goff et al., 2007; Yeh et al., 2010).

Existing data sources have complementary potential to provide surveillance information across the life span. Enhancing the use of current data sources requires coordination of data collection efforts, harmonization of some elements, expansion to include patient outcomes, and community-tailored items. Coordination of data collection efforts across federal, state, and local systems as well as healthcare delivery systems has great potential for future surveillance efforts. Such efforts should include, to the extent possible, standard definitions of key risk factors and outcomes, interventions, and a mechanism to link subjects and providers across the different data sources. The committee believes that serious consideration should be given to the scientific and cost considerations as well as the ethical and privacy issues associated with the use of a unique personal health identifier so that results can be compared within and across different geographical areas.

The increase in value of the multiple federal data sets that collect information from subjects, patients, healthcare providers, and healthcare insurers would be increased substantially if linkages across data sources were possible. The use of multiple informants to measure the burden of cardiovascular and chronic lung disease risk factors, behaviors, treatments, and outcomes could provide a comprehensive active surveillance system capable of providing information that could be used by multiple stakeholders to analyze, understand, and act effectively.

The committee has proposed a framework (Figure 7-1) for organizing surveillance efforts that is based on the core concepts of the life course and the role of prevention. This framework incorporates both traditional data sources such as surveys, registries, cohort studies, and vital statistics, as well as evolving or novel sources that include health services and patient-generated data as well as and environmental data (illustrated in Figure 7-2). It must be noted that integrating data from these multiple sources will not be an easy task. Multiple stakeholders must reach agreement about what needs to be collected and integrated, and mechanisms for doing so must be developed and implemented. Such efforts will require investments of both dollars and time and progress will likely occur in a series of steps taken over a number of years.

The recommended framework also provides for a system that is relevant to multiple users at various levels, for example:

- At the national level for developing policies, setting funding priorities, and identifying research needs;
- At the state or regional level to aid in planning and allocating resources for various programs, services, and educational and policy initiatives;
- At the county or other local level for developing and organizing public health and healthcare services, developing and advocating health promotion and disease prevention policies, and educating and mobilizing community leaders and members; and
- At the family and individual level for guiding personal changes in lifestyle and environment.

Recommendation 4

The committee recommends that the group that oversees and coordinates surveillance activity be charged with

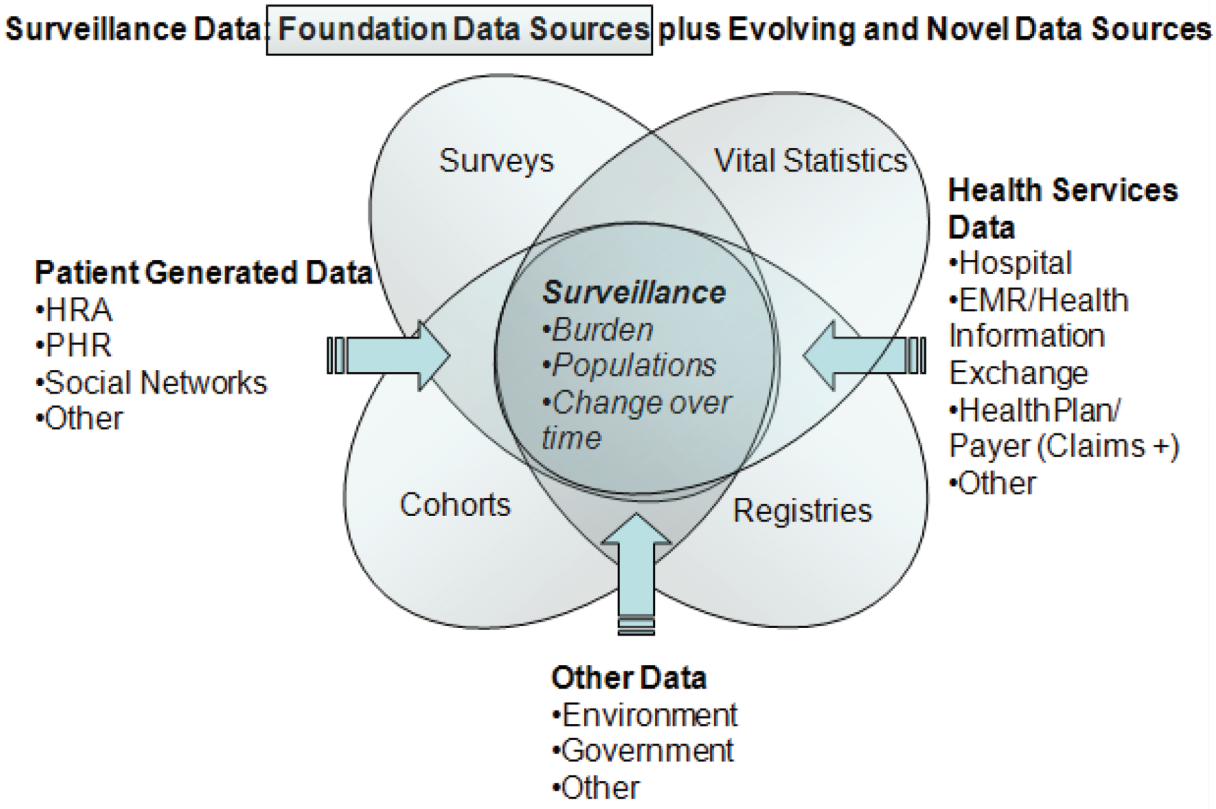

FIGURE 7-2 Traditional and evolving data sources for surveillance.

- **Selecting surveillance indicators and, periodically, undertaking a review of the surveillance system in order to identify and incorporate necessary modifications;**
- **Improving collaboration and coordination among federal, tribal, state, and local agencies and non-governmental organizations around the collection, compilation, and dissemination of surveillance information;**
- **Collecting and making available all types of surveillance data (survey, registry, EHR) at the most granular level consistent with protection of data privacy and confidentiality and, when feasible, linked with other data sources (i.e. clinical databases, public health data);**
- **Formation of public–private partnerships with the nongovernmental health sector; and**
- **Development of data sets for surveillance sources that can be made broadly accessible to a variety of users to support and guide action to improve health at the national, state, and local levels.**

While the working group will provide direction as outlined above, a mechanism must be established to facilitate implementation of the enhanced and integrated system as it evolves. Several options exist for such a mechanism, two of which are described here. One option is the National Center for Health Statistics (NCHS) whose mission is "to provide statistical information that will guide actions and policies to improve the health of the American

people" (NCHS, 2009). The Health and Human Services Health Indicators Warehouse is operated by NCHS, and surveys and data systems in the NCHS purview include:

- National Ambulatory Medical Care Survey
- National Home and Hospice Care Survey
- National Hospital Ambulatory Medical Care Survey
- National Hospital Discharge Survey
- National Nursing Home Survey
- National Survey of Ambulatory Surgery
- National Survey of Residential Care Facilities

NCHS has a Board of Scientific Counselors that provides advice and makes recommendations about research and about new approaches for monitoring and evaluation of health-related policy changes. NCHS also facilitates the work of the Interagency Working Group on Summary Measures of Health (IAWG), which is composed of representatives from federal agencies and which is a forum for exchange of perspectives on summary measures of health.

Arguments in favor of designating NCHS as the office to coordinate the surveillance system include its portfolios of national surveys, which provide key national information on prevalence and distribution of disease and associated risk factors. NCHS also collects data on many chronic diseases and vital statistics, so it would be in a good position if the system were to expand to include chronic diseases in general. Other advantages of NCHS are that it is a federal statistical agency with independent judgment over its data because of its congressional designation, and it collects individual identifiers that enable linkage of data from its premier national survey, the National Health Interview Survey (NHIS), to Medicare data, national death records, and other federal data. Key NCHS surveys, including the NHIS, use multistage sampling designs, which enable them to sample states and other geographic areas. The NHIS is an in-person survey, which is entirely appropriate for a national benchmark survey. The National Health and Nutrition Examination Survey (NHANES) plays an important surveillance role because it does physical exams, collects biological specimens, and collects interview data. The State and Local Area Integrated Telephone Survey (SLAITS), an NCHS telephone survey that uses the sampling frame of the National Immunization Survey, could be adapted to be comprehensive and potentially could meet state and locally defined data needs. NCHS, together with the National Committee on Vital and Health Statistics and the HHS Data Council, clearly articulated a vision for health statistics consistent with the perspective and recommendations of this Committee (NCHS, 2002).

NCHS has many strengths but also some limitations. The main NCHS survey, the NHIS, relies on methods that produce representative samples nationally and at the state level, but these methods do not provide locally representative samples and data (e.g., at the substate or county level) to support local public health action to prevent and control chronic diseases. Coordination among the NCHS surveys and with other surveys conducted by CDC or other federal agencies needs to be strengthened to meet the goals of a nationally integrated system. Furthermore, NCHS does not encompass registry data, which are very important to measuring incidence and evaluating treatment of some chronic diseases; has limited capability in web-based query systems; and does not have established relationships with many stakeholders important to collecting and effectively disseminating surveillance data.

The National Heart, Lung, and Blood Institute (NHLBI) is another alternative mechanism that could be used to implement the decisions of the recommendation 1 working group. As the National Cancer Institute relates to the Surveillance Epidemiology and End Results (SEER) cancer surveillance system, so could NHLBI function in relation to a surveillance system for cardiovascular and chronic lung disease. The cancer-based SEER program collects information from population-based cancer registries that cover approximately 26 percent of the population. NCI staff are responsible for overseeing the quality of the system and work with registry staff to ensure data quality. They also implement the decisions of the Change Control Board (CCB), which is responsible for evaluating new features and potential changes to algorithms, database structure, and hardware infrastructure. The NCI also compiles and disseminates reports and findings regarding cancer and interacts, a function that NHLBI currently fulfills for heart and vascular diseases, lung diseases, blood diseases, and sleep disorders.

Arguments in favor of designating NHLBI include its expertise in cardiovascular and chronic lung disease and its history of funding data collection on these topics. Furthermore, it already works closely with many organiza-

tions implementing registries for CVD and could do so for organizations with registries developed for COPD, an important strength if the surveillance system is to meet the data needs of stakeholders nationally and at state and local levels.

Drawbacks include the fact that NHLBI would need to develop capacities it does not currently have or partner with others to collect and manage large data streams, conduct large surveys, marshal the resources necessary to generate data for state and local surveillance, and provide easy access to such data for a wide array of stakeholders. Furthermore, the institute is more focused on a particular set of diseases, so if the system were to expand to chronic disease more broadly, NHLBI would have difficulty expanding such a system without overlapping with other NIH institutes.

To further understand the basis and trajectories of cardiovascular and chronic lung diseases, the information collected by the system must be available and accessible to a variety of stakeholders as discussed in Chapter 6. While data from national surveys conducted by the federal, state, or local governments are usually readily available, private sources of data are frequently inaccessible or accessible only with great difficulty. A greater national investment is needed to ensure that chronic disease surveillance data are accessible to potential data users with a wide range of technical capacities. Federal, state, and local public agencies could play a stronger leadership role in making data accessible to all sectors of society. This role would be especially important to ensure the relevance and accessibility of such data for chronic disease surveillance and policy making at state and local levels as well as nationally.

Recommendation 5

The committee recommends that the Secretary of HHS designate a federal office with the following responsibilities:

- **Producing and disseminating regular surveillance reports and key indicators of progress that support and stimulate action aimed at improving health and reducing disparities at the national, state, and local levels;**
- **Assuring that the surveillance data are accessible to a broad spectrum of users (e.g., public health agencies, health systems, researchers, policy makers, and advocacy groups) at all levels while protecting privacy and documenting the extent of that use; and**
- **Implementing the recommendations of the national working group recommended in Recommendation 1.**

As discussed earlier in this chapter, the life-course perspective is important to understanding the trajectory of chronic diseases. Also needed are comparable data that enable analysis across different subpopulation groups and geographic levels and that can be linked across data sources. Existing data collection mechanisms provide valuable information that, with enhancements, can serve to meet the surveillance needs for CVD and chronic lung disease.

Recommendation 6

The committee recommends that HHS coordinate with voluntary bodies operating disease registries to promote collection and harmonization of data.

Recommendation 7

The committee recommends that governmental and nongovernmental organizations enhance existing national data sources in the following manner:

- **Information on all elements of the recommended framework should be collected on the U.S. population across the life span, with special attention paid to collecting information on diverse and changing populations, including information on disparities.**

- **A minimum subset of actionable indicators as identified by the working group should be collected using comparable measures at the national, state, and local levels.**
- **Data should be increasingly linked across health domains and data sources.**

Effective interventions to prevent CVD and chronic lung disease require tracking information at multiple geographic levels—local, state, and national. Likewise, federal healthcare reform legislation has established a national healthcare coverage and delivery policy, yet much of the implementation will occur at the state level. State and local policy makers, public health leaders, and health professionals need feedback afforded by surveillance systems to inform them of the magnitude of disease and disparities within their geographic areas compared to other areas, as well as the outcomes of their efforts.

Surveillance needs differ among communities. Community-tailored survey items will be necessary to understand the extent to which conditions vary by characteristics such as socioeconomic status, race/ethnicity, or geographic setting (e.g., urban versus rural). As discussed in Chapter 4, these factors are frequently associated with health disparities. To foster efforts to reduce these disparities, a surveillance system must be able to provide data for analysis of disparities not only at the national level but also at the regional, state, and local levels. Furthermore, the system will be most beneficial if comparisons can be made between and among various communities that require collection of comparable data.

Recommendation 8

The committee recommends that HHS develop a cardiovascular and chronic pulmonary disease survey question bank and technical support for use by tribal, state, and local agencies; nongovernmental organizations; and individual researchers for the purpose of enhancing the quality and comparability of population health surveys in order to identify trends in risk factors, diseases, treatments, and outcomes.

As discussed in Chapter 6, there is great potential for the use of electronic health records as sources of surveillance information. Currently, those records focus primarily on recording clinical information (e.g., diagnoses, laboratory work, and treatments). Chapters 2 and 3 described the importance of behavioral, social, and physical environmental risk factors in the development of cardiovascular and chronic lung disease. The Office of the National Coordinator for Health Information Technology (ONCHIT) has the responsibility to identify the minimum data to be collected for EHRs and is in a position to take action that would significantly enhance the surveillance information contained in EHRs.

Recommendation 9

The committee recommends that the Office of the National Coordinator for Health Information Technology expand the minimum data for electronic health records to include behavioral, social, and environmental risk factors for cardiovascular and chronic lung diseases in validated, interoperable ways in order to enhance the quality of surveillance data for these conditions.

Because EHRs are currently in use in only a minority of hospitals and practices, several interim steps are needed before their potential can be realized. Expansion of EHRs to the majority of clinical care settings will require significant investment in purchasing necessary equipment and software as well as staff training. Additional resources will need to be devoted to major issues such as interoperability of EHR systems and harmonization of data standards.

Many existing sources of surveillance information provide high-quality data that are critical to understanding the trajectory of cardiovascular and chronic lung diseases. However, those data lack standardization and cannot be linked across sources, and many of them are not readily accessible. Furthermore, there is a need for collection of data that facilitates analysis by various demographic variables, such as race/ethnicity, socioeconomic status, and geography. The committee believes the recommendations provided in this report lay the foundation or framework for the development of the complex, interdependent system needed.

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Appendixes

Appendix A

Contents

Appendix A

Data Collection Approaches

COHORT STUDIES

Atherosclerosis Risk in Communities (ARIC)

Main Purpose of Study: The main purpose of the community surveillance component of the ARIC Study is to continuously monitor and independently validate coronary heart disease (CHD) events (acute myocardial infarction [MI] and death due to coronary heart disease) and acute decompensated heart failure occurring among residents of four geographically defined communities in the United States in order to evaluate trends in mortality, incidence, case fatality rates, and medical care by age, gender, race, community, and time.

The ARIC Study also includes monitoring and validating events among cohort participants (random sample of 15,792 men and women from four communities enrolled in 1987–1989). In addition to the CHD endpoints above, clinically recognized strokes among cohort participants are also identified and validated through surveillance procedures. All hospitalizations among the cohort are identified and recorded, but only those mentioned above are independently validated. Investigations using endpoints captured in cohort surveillance has led to over 800 published reports regarding the prevalence of cardiovascular disease and risk factors among the cohort as well as the role of established and novel risk factors in predicting disease. The information relates to the ARIC Study's community surveillance component unless noted otherwise.

Sample: ARIC community surveillance is a continuous retrospective, hospital-based surveillance study. Population denominators are estimated using interpolation and extrapolation for 1990 and 2000 U.S. Census population estimates.

Through community surveillance, the ARIC Study enumerates and validates cases (events) of hospitalized MI and CHD deaths occurring after January 1, 1987, in 35- through-74-year-old male and female residents of the four ARIC Study communities: Forsyth County, North Carolina; Jackson, Mississippi; suburbs of Minneapolis, Minnesota; and Washington County, Maryland.

The population of men and women age 35–74 in these four communities was approximately 406,000 in 2007. The eligible age range of ARIC surveillance was expanded to age 84 beginning in 2005, bringing the surveillance population to a total of approximately 447,000 men and women age 35–84.

Community surveillance was also expanded to include surveillance of hospitalized heart failure beginning in 2005 for community residents age 55 years and older. The ARIC Study is currently funded to conduct surveil-

lance for events occurring through December 31, 2010. A renewal is pending that will extend surveillance through December 31, 2014.

All residents of the four geographically defined communities are included in ARIC community surveillance regardless of race or ethnicity. The white minority in Jackson and the black minority in Forsyth County are oversampled. The number of persons reported to be neither black nor white has been small in these communities and currently produce unstable event rates. Both men and women of all race or ethnic groups are eligible for selection in ARIC community surveillance.

Frequency of Collection and Sources of Data: ARIC community surveillance identifies, samples, and investigates hospitalizations on a continuous basis and produces annual event rates in the four communities. Sources include hospitalized events for acute myocardial infarction are identified from electronic lists of discharges obtained for catchment area hospitals on an ongoing basis. Hospitalizations selected (sampled) for investigation are identified and medical records for those events are obtained by trained ARIC medical record abstractors. Medical records are abstracted using a standardized, web-based data entry system.

Fatal events for investigation are identified through electronic lists of deaths obtained from local or state health departments. Deaths are sampled based on underlying cause of death codes. Sampled death certificates are obtained and abstracted by trained ARIC staff. Death with an underlying cause of death code that is related to CHD and occurring out-of-hospital are targeted for further investigation through telephone interview with next of kin or witness. The decedent's physician is also identified from the death certificate and sent a questionnaire requesting information relevant to classification of the death. If a coroner or medical examiner, information is also obtained if appropriate. For ARIC cohort participants, hospitalizations for investigation are identified through an annual follow-up telephone interview conducted by ARIC staff. In addition to the events noted above, stroke related hospitalizations are also indentified among cohort members. Any hospitalization reported by a cohort member through annual follow-up telephone interviews or found through routine community surveillance is identified and obtained for abstraction. Deaths among cohort members are identified either through annual follow-up contact, monitoring of electronic death files from local and state health departments, or by on-going monitoring of obituaries in the study communities by ARIC staff.

Mode of Data Collection: Data on hospitalizations and deaths are collected manually through detailed abstraction of medical record or death records. Data from next of kin for out-of-hospital deaths are collected through a telephone interview. Mailed surveys are also used to solicit information from physicians identified on death certificates for selected cases.

Specific Questions Related to CVD, COPD, Asthma, and/or Diabetes: In ARIC community surveillance, information collected on sampled hospitalized myocardial infarction and heart failure events include specific items on medical history and comorbid conditions such as chronic pulmonary disease and diabetes. Furthermore, all discharge codes for sampled cases are also recorded. However, hospitalizations for chronic pulmonary disease, asthma, and/or diabetes are not specifically investigated in ARIC community surveillance.

Among ARIC cohort participants, all hospitalizations for any reason are indentified and ICD-9-CM discharge diagnoses and procedure codes recorded. Those related to myocardial infarction, heart failure, and stroke are investigated further as noted above. During the annual follow-up interview of cohort participants, questions are asked that relate to pulmonary signs and symptoms as well as self-reported physician diagnosis of diabetes.

Information Obtained: Measures available through ARIC community surveillance are summarized as follows:

- Incidence: Annual incidence rates of hospitalized acute myocardial infarction (1987–2014)
- Annual incidence rates of hospitalized acute decompensated heart failure (2005–2014)
- Annual mortality rates due to coronary heart disease (1987–2014)
- Annual mortality due to sudden cardiac death (1987–2014)
- Case fatality: Annual case fatality rates (through one year) after hospitalized acute MI (1987–2014)
- Clinical care information: Procedures during hospital stay for hospitalized acute MI (* includes data on time since event onset): Cardiac catheterization, coronary angiography, coronary angioplasty,* coronary atherectomy,* Swan-Ganz catheterization, echocardiography, coronary bypass surgery,* intracoronary thrombolytic therapy,* intravenous thrombolytic therapy,* aortic balloon pump, MRI scan of heart, exercise

stress test, Holter monitoring, coronary stent placement,* implanted defibrillator,* coronary CT, closed chest massage or cardioversion, and other procedures recorded as open text
- Procedures during hospital stay for hospitalized acute decompensated heart failure: Chest X-ray, echocardiography, coronary angiography, cardiac radionuclide ventriculogram, magnetic resonance imaging, cardiac CT, stress tests
- Medical therapy during hospital stay or discharge for hospitalized acute MI: Nitrates, calcium channel blockers, beta-blockers, digitalis, lidocaine, Coumadin, aspirin, ACE or angiotensin II inhibitors, heparin infusion, antiplatelet agents, lipid lowering medication
- Medical therapy during hospital stay or discharge for hospitalized acute decompensated heart failure: CE inhibitors, angiotensin II receptor blockers, beta blockers, digitalis, diuretics, aldosterone blocker, lipid lowering agents, nitrates, hydralzaine, IV inotropes
- Diagnostic information for hospitalized acute MI: Biomarkers (total CK, CK-MB, total LDH, troponin I, tropoinin T, BNP, Pro-BNP, serum creatinine)
- Electrocardiographic information: Copies of up to three electrocardiograms with Minnesota coding for each
- Diagnostic information for hospitalized acute decompensated heart failure: Diagnostic findings including measures of ejection fraction from imaging, biomarkers including BNP, proBNP, troponin I, troponin T, serum creatinine, BUN

Information Not Obtained: Measures available through ARIC community surveillance are summarized as follows:
- Prevalence: ARIC community surveillance designed to capture incident and recurrent hospitalized MI and heart failure. Prevalence measures of these conditions in the population are not obtained.
- Functional Health Outcomes: Not captured in ARIC community surveillance
- Risk Factor (including stressor): Not captured in ARIC community surveillance

Demographic Characteristics Collected: Age, sex, race or ethnic group, Hispanic or Latino origin, type of health insurance, patient address (geocoded to provide latitude and longitude and linked to census data on neighborhood socioeconomic status).

Who Pays for Data Collection?: ARIC surveillance is funded by a contract with the National Institutes of Health, National Health, Lung, and Blood Institute.

Dissemination of Data: Public use data files are created and updated annually and are available through the NHLBI project office.

The Cardiovascular Health Study (CHS)

Main Purpose of Study: The Cardiovascular Health Study is an NHLBI-funded observational study of risk factors for cardiovascular disease and stroke in adults 65 years or older.

Sample: In June 1990, four field centers completed the recruitment of 5,201 participants. Between November 1992 and June 1993, an additional 687 African Americans were recruited using similar methods. The sample was drawn from four field centers. They are located in Forsyth County, North Carolina; Sacramento County, California; Washington County, Maryland; and Pittsburgh, Pennsylvania. The only geographical level of collection of data was by field center. Minorities are oversampled. Men and women are included. A stipulation of the study was that participants be over 65 or older.

Frequency of Collection and Sources of Data: Until 1999, semiannual contacts alternated between clinic examinations and telephone contacts, during which information about hospitalizations and potential cardiovascular events was collected. Since 1999, participants have been contacted twice a year by telephone to collect limited data, including medication data, and to identify all hospitalizations and potential cardiovascular events. Participants were also invited to participate in a clinic or home visit as part of an ancillary study called CHS All Stars Study in year 18; semiannual phone calls continue. Presently collecting data for year 21. The CHS All Stars Study is an ancillary study that focuses on reexamining the long-term survivors of CHS to determine the likelihood of maintaining

function later in life. The primary source of data is participant examinations and interviews. Hospital records were obtained to confirm self-reported events, and CMS (Medicare) records were searched to capture any missed events.

Mode of Data Collection: The baseline examination consisted of a home interview and a clinic examination that assessed not only traditional risk factors for cardiovascular disease but also measures of subclinical disease, including carotid ultrasound, echocardiography, electrocardiography, MRIs, and pulmonary function. Major exam components were repeated during annual follow-up examinations through 1999. Cranial MRI scans, retinal photography, and tests of endothelial function were added as new components.

Specific Questions Related to CVD, COPD, Asthma, and/or Diabetes: Cardiovascular disease was measured and adjudicated by a panel of doctors based on hospital records. Chronic pulmonary disease was measured by self-report and periodic spirometry measurement. Asthma was measured through self-report. Diabetes was measured through self-report, periodic measurement of blood glucose level, and annual review of medications.

Information Obtained: Incidence, prevalence, functional health outcomes, risk factors, clinical care information, demographic characteristics.

Who Pays for Data Collection?: CHS was originally funded through a contract from the National Heart, Lung, and Blood Institute (NHLBI). Additional funding has been obtained through a renewal of the NHLBI grant to continue cohort follow-up, from NINDS, the NIA, and a wide number of ancillary studies.

Dissemination of Data: There are two means of obtaining data: (1) Researchers can contact the Collaborative Health Studies Coordinating Center to be sponsored by a CHS investigator. They would then submit a paper proposal to be reviewed by the CHS Publications and Presentations Committee and the Steering Committee. Proposed papers would be reviewed for consistency with the goals of CHS, lack of overlap with other work, scientific integrity, and evidence of collaborative authorship, including junior investigators. (2) Data are also available as a limited access data set with NHLBI. Applicants can make a direct enquiry to NHLBI to obtain that data.

Additional Comments: Pittsburgh population entirely urban; other three field centers recruited mixed urban and rural populations; participating academic institutions include the University of Washington, the University of California–Davis, the Johns Hopkins University, Wake Forest University School of Medicine, University of Pittsburgh, University of Vermont, University of Maryland, Baltimore, University of Arizona, University of Wisconsin, and Tufts New England Medical Center; standard protocols for the identification and adjudication of cardiovascular events were implemented during follow-up. The adjudicated events are CHD, angina, heart failure (HF), stroke, transient ischemic attack (TIA), claudication, and mortality. Other patient information was collected through a wide array of measures.

COPDGene® Study

Main Purpose of Study: Scientific researchers are conducting an investigation to find the genes that cause a susceptibility to developing COPD. This groundbreaking study, a $37 million grant awarded by the National Heart, Lung, and Blood Institute, has the potential of changing what is known about COPD and COPD treatment. Dr. James Crapo of the National Jewish Health in Denver, Colorado, along with Dr. Edwin Silverman of the Brigham and Women's Hospital in Boston, Massachusetts, are conducting a genetic epidemiology study of COPD—a study to characterize COPD in the U.S. population and to find the genes that create a risk for developing this disease. The study brings together a large cohort of individuals who have COPD or are at risk for developing COPD. The study will analyze genetic variations across the entire human genome to identify the primary genes that determine why some individuals are more susceptible to developing COPD than other individuals. The COPD Foundation Registry serves as a valuable supplemental source of patients for the COPDGene® Study cohort. The COPDGene® Study has a highly characterized cohort of patients, including African Americans.

The COPDGene® Study is in the process of creating the largest, well-characterized set of COPD and control subjects ever assembled for pulmonary disease research. In addition to identifying COPD susceptibility genetic determinants, important advances in characterization of the natural history of COPD and its phenotypes can be anticipated, along with identification of new, well-characterized COPD subtypes. Improved understanding of COPD subtypes and genes controlling susceptibility to COPD could lead to novel pathophysiological insights, refined diagnostic criteria, and new approaches for pharmacological treatments for COPD.

An interesting aspect of the COPDGene® Study is that participating patients have agreed to be contacted for other studies. So in essence, this study acts as a cohort of patients who are ready to participate in other studies. Thus, the COPDGene® Study cohort is also a registry for participation in other studies.

The COPDGene® Study includes the following: Creation of a large cohort of subjects at risk for or expressing one of the various stages of COPD (GOLD grades 1–4). This cohort will be clinically phenotyped and all subjects will undergo HRCT, which will be quantitatively analyzed to divide the cohort into unique subtypes of COPD. A genome-wide association study is being conducted on the cohort resulting in fine mapping of the genetic determinants for susceptibility to develop COPD. The impact of these identified COPD susceptibility genes on each of the CT-defined COPD subtypes will be determined. The cohort of patients is being followed longitudinally to identify the clinical phenotypes, CT subtypes, and genotypes that determine risk for COPD progression, morbidity, and mortality. While the initial emphasis in the design of the cohort was on COPD, all subjects in the cohort will be smokers, and the cohort analysis will be expanded to include other smoking-related diseases such as cardiovascular disease and cancer. Finally, the ultimate goal of this project is to carry out translational studies to validate new therapies that are personalized for subjects with specific subtypes of COPD.

The study, which was originally scheduled to be completed in 5 years, has surpassed enrollment projections and will be concluding enrollment in the next month, 1 year ahead of schedule. In order to identify the genetic basis of COPD, a study group of 10,000 individuals will be formed. Nineteen medical centers across the U.S. host the clinical evaluations of eligible individuals that want to participate in the study. The clinical evaluations are being conducted physiologically and radiographically, meaning that the individual takes a spirometry test, tests on a 6-minute walk, and scores on a BODE scale (body mass index, degree of airflow obstruction, degree of dyspnea, and exercise capacity). The individual is also given a chest CT scan, completes a set of questionnaires, and donates about 30cc (6 teaspoons) of blood for genetic analysis.

The aims of the COPDGene® Study are as follows:

- Specific Aim 1: Build Cohort of 10,000 Smokers (10+ pack years). Clinically phenotype COPD cases and control subjects for genetic, epidemiologic, natural history, and pharmacologic intervention studies.
  - — Sample Size by GOLD Criteria
    - ♦ Non-Smokers without COPD (100 subjects)
    - ♦ Smokers without COPD (4,000 subjects)
    - ♦ Smokers with possible COPD, GOLD grade 1 (800 subjects)
    - ♦ Smokers with possible COPD, GOLD grade U (1,100 subjects)
    - ♦ Smokers with COPD, GOLD grades 2–4 (4,000 subjects)
  - — Sample Size by Race
    - ♦ COPD case/control cohort—Non-Hispanic white (n = 6,700 total)
    - ♦ COPD case/control cohort—African American (n = 3,300 total)
- Specific Aim 2: CT Phenotype Cohort—Characterization of Subtypes of COPD.
  - — Use HRCT (inspiration and expiration scans) to subdivide the cohort into groups expressing unique airway disease (inflammation) and lung parenchymal subtypes (emphysema) of COPD.
  - — Validate quantitative indexes (by HRCT) of the emphysema and airway inflammatory disease subtypes.
    - ♦ Percent of specific lung regions with low attenuation
    - ♦ Airway wall thickness of 3rd–6th generation airways
    - ♦ Percent gas trapping identified by expiratory CT scan
- Specific Aim 3: Genotype Cohort. Genome-wide association study using a phased approach.
  - — A genome-wide panel of SNPs will be tested for association with COPD.
  - — Confirmation of SNPs to identify genomic regions for intensive investigation.
  - — Mapping of 50 genomic regions to identify susceptibility genes for COPD.
  - — Fine mapping of candidate genes to identify susceptibility alleles and/or high risk haplotypes.
  - — Assess the association of genetic variants in the identified COPD susceptibility genes with CT-defined COPD subtypes.

- Specific Aim 4: Longitudinal Follow-up of This Cohort to
  - — Assess risk factors for COPD progression, morbidity, and mortality
  - — Determine which CT phenotypes and genotypes identify asymptomatic subjects who are at high risk for progression to overt COPD
  - — Develop biomarkers for COPD and COPD subtypes that relate to disease progression and prevention
- Specific Aim 5: Expand Analysis of Cohort to Evaluate Other Smoking-Related Diseases and/or Comorbidities.
  - — Cardiovascular disease
  - — Stroke
  - — Cancer
  - — Musculoskeletal disease
  - — Depression/cognitive dysfunction
- Specific Aim 6: Use Phenotyped and Genotyped Subcomponents of Cohort for Translational Studies to Validate New Therapies.
  - — Pharmacologic interventions in specific subtypes of COPD
  - — Identification of asymptomatic smokers at high risk for disease progression and development of preventive therapies
  - — Use identified biomarkers that relate to disease progression and prevention to assess efficacy of new therapies

Sample: The goal of the COPDGene® Study is to enroll 10,000 patients. The participating centers enrolling patients are located across the United States. Geographic levels included are state and national (United States only). Goal is to frequency match for gender distribution within each racial group for the case-control component of this project. Approximately 33% of the final study sample will be African American.

Subjects must be at least 45 years old, and both men and women may participate.

Frequency of Data Collection and Sources of Data: Data are collected at the initial study visit, and longitudinal data are collected at 6-month intervals following the visit. Sources of data include questionnaires collected at the visit, blood and CT scan analysis, longitudinal follow-up questionnaires, and subject medical records if available.

Mode of Data Collection: In-person examination or biomarker data collection, administrative data, mailed surveys, and automated telephony surveys

Specific Questions Related to CVD, COPD, Asthma, and/or Diabetes: Questions are asked related to comorbidities that include CVD, chronic pulmonary disease, asthma, and diabetes.

Information Obtained: Incidence, prevalence, functional health outcomes, and risk factors, including stressors, clinical care information, and demographic characteristics

Cost of Survey/Registry: Almost 40 million dollars

Who Pays for the Data Collection?: The National Institutes of Health (NIH) and the COPPD Foundation

Dissemination of Data: Data files are available online to authorized study investigators either through the COPDGene® Study website or through the National Institutes of Health dbGaP resource. Authorized COPDGene® investigators have access through the COPDGene® website. All other data users must access data through dbGaP. All data to be provided externally shall be de-identified. This study is novel and unique since it will allow transparent and public access the study's data. Investigators, government, and industry shall have access to the data.

The Coronary Artery Risk Development in Young Adults (CARDIA) Study

Main Purpose of Study: The Coronary Artery Risk Development in Young Adults (CARDIA) Study is a study examining how heart disease develops in adults.

Sample: 5,115 black and white men and women across four cities: Birmingham, Alabama; Chicago, Illinois; Minneapolis, Minnesota; and Oakland, California. The study was designed so that there are approximately 50% blacks, 50% whites; 50% males, 50% females; 50% aged 18 to 24, 50% aged 25–30; 50% who have not completed high school, and 50% who have completed high school.

From the official sample size for the study n = 5,115: Birmingham, Alabama: 3,252 eligible participants contacted, 1,811 (55.7%) made appointments; of those 1,178 (65.0%) examined; Chicago, Illinois: 2,205 eli-

gible participants contacted, 2,149 (97.5%) made appointments; of those 1,109 (51.6%) examined; Minneapolis, Minnesota: 2,473 eligible participants contacted, 1,777 (71.9%) made appointments, of those 1,402 (78.9%) examined; Oakland, California: 2,203 eligible participants contacted; 2,047 (92.5%) made appointments; of those 1,426 (69.7%) examined. A majority of the initial group (1986) has participated in follow-up examinations: 1987–1988 (90%); 1990–1991 (86%); 1992–1993 (81%); 1995–1996 (79%); 2000–2001 (74%); 2005–2006 (72%)

Frequency of Collection and Sources of Data: Study initiated in 1986 (Year 0), with the same participants asked to participate in follow-up examinations in 1987–1988 (Year 2); 1990–1991 (Year 5); 1992–1993 (Year 7); 1995–1996 (Year 10); 2000–2001 (Year 15); 2005–2006 (Year 20). Core study exam results; Medical history; Obesity questionnaires; Psychosocial; Physical measurement; Pulmonary function testing and questionnaire; Electrocardiogram; Echocardiography; Genetic studies

Mode of Data Collection: In-person interview on medical and family history; medical exams; anthropometry; blood test

Specific Questions Related to CVD, COPD, Asthma, and/or Diabetes: Core Study: blood pressure, lipids, lipoproteins, apoproteins, cotinine, SMAC 12, fasting insulin, fasting glucose, oral glucose tolerance test, CBC, Lp(a), fibrinogen, stored plasma, stored serum, serum creatinine, urinary creatinine, uric acid, c-reactive protein, albuminuria, interleukin-6; Pulmonary function; Electrocardiogram; Echocardiography, HbA1C

Information Obtained: Incidence, prevalence, quality of life, discrimination, height, weight, skinfold fat, blood pressure, cholesterol, other lipids, other chemistries (insulin and glucose), physical activity/fitness, diet history, food frequency, obesity questionnaire, personal history, substance use (tobacco and alcohol), behavioral and psychological variables, stress, anxiety. Subclinical atherosclerosis measured via echocardiography during Year 5 and 10, computed tomography during Year 15 and 20, carotid ultrasound during Year 20. Demographic information includes age, race/ethnicity, geographic region, education.

Who Pays for Data Collection?: Group of contracts funded by the National Heart, Lung, and Blood Institute (NHLBI); brain MRI component is included in the Year 25 exam that NIA is funding.

Dissemination of Data: CARDIA uses a distributed data system with current data. In this system the Field Center PIs, the Steering Committee Chair, and the Project Office (NHLBI) get a full copy of the data. Proposals for manuscripts are approved by the study's Publications and Presentations Committee. All approved manuscripts require a CARDIA-approved investigator to be associated with the manuscript. Investigators with approved manuscripts can request manuscript specific data sets from the Coordinating Center. Investigators can also request a data repository data set (formerly known as Limited Access Dataset) directly from NHLBI. These data, however, have a 5-year lag (soon to be changed to a 3-year lag) and have been winsorized to protect participant confidentiality.

Eight Americas

Purpose: The Eight Americas explore the causes of disparities in race-counties that inform specific public health intervention policies and programs.

Sample: The sample includes the entire U.S. population (all ages) divided into eight distinct subgroups. Building blocks for these groups were a combination of race and county of residence. Race-county units were combined based on socioeconomic and geographical indicators, including location of county of residence, population density, race-specific county-level per capita income, and cumulative homicide rate. Smaller counties were merged with adjacent counties to form units with total population of at least 10,000 males and 10,000 females. Merged county units also formed to account for changes in county status and county lines. There are 2,072 counties.

Souces of Data: For 1982–1989, interpolated age-, sex-, race-, and county-specific population figures using 1980 and 1990 Census figures. Used bridged-race population estimates released by National Center for Health Statistics (NCHS). NCHS mortality statistics. Behavioral Risk Factor Surveillance System for health plan coverage and health care utilization. Global Burden of Disease database for life expectancy and probabilities of death for international comparisons.

Information Obtained: Race, race-specific county income, average income per capita, percent completing high school, sex, and age.

Who Pays for Data Collection?: Centers for Disease Control and Prevention, the Association of Schools of Public Health, the National Institute on Aging.

Framingham Heart Study

Main Purpose of Study: The Framingham Heart Study is a prospective, longitudinal observation of three generations of living population for CVD endpoints and other common chronic diseases.

Sample: Size at entry: 15,447 men and women in five cohorts residing in or near Framingham. Local level data only. Minorities were not oversampled. Response rate: 70–80% over the 60+ years of the study. Age groups included at entry:

- Original Cohort: 29–62 years
- Offspring Cohort: less than 10 to 70 years
- Third Generation and New Offspring Spouses Cohort: 19 to 79 years
- Omni Group 1 Cohort: 20 to 79 years
- Omni Group 2 Cohort: 20 to 70+ years

Frequency of Data Collection: Health history updates every 2 years, clinic exam every 2 to 6 years

Sources of Data: Hospital discharge, medical records, population interviews, disease registries

Mode of Data Collection: Interviews and measurements from in-person examinations and biomarker collection; health history updates by mailed questionnaire or telephone interview; follow-up medical records from health care providers.

Specific Questions Related to CVD, COPD, Asthma, and/or Diabetes: Extensive (variables posted on SHARe website, http://www.ncbi.nlm.nih.gov/sites/entrez?db=gap)

Information Obtained: Incidence, prevalence, functional health outcomes, and risk factors, including stressors, clinical care information

Who Pays for Data Collection?: NHLBI Contract and NIH grants

Dissemination of Data: Data request applications are available online. Data are available through research proposals submitted online and approved by relevant review committees. FHS variables are posted on the Framingham Heart Study website, www.framinghamheartstudy.org. Queries may be sent to the FHS research committee. Principal investigators with proposals approved by the review committees and with IRB approval and data distribution agreements can obtain access.

Millennium Cohort Study

Purpose: In the late 1990s, the U.S. Department of Defense and Congress identified the need for coordinated epidemiological research to determine how military occupational exposures, including deployment-related exposures, affect long-term health. The Institute of Medicine more specifically defined the importance of a large, prospective study for evaluating exposures and a broad spectrum of important health outcomes. The Millennium Cohort Study was designed, in collaboration with all military services and the Department of Veterans Affairs, to meet these research challenges.

The objectives of the Millennium Cohort were (1) to evaluate chronic diagnosed health problems, including hypertension, diabetes, and heart disease, among military members, in relationship to exposures of military concern and (2) to evaluate long-term subjective health, including chronic multi-symptom illnesses, among military members, especially in relationship to exposures of military concern.

Sample: Launched in the summer of 2001, the Millennium Cohort Study began enrolling a representative sample of U.S. military personnel, both active duty and Reserve and National Guard members, who agreed to participate in follow-up well past their time in service, for up to 21 years. There are more than 150,000 consenting Millennium Cohort Study members. Currently, participants that enrolled in the 2001 survey cycle, Panel 1, include over 77,000; participants that enrolled in the 2004 survey cycle, Panel 2, include an additional 31,100; and participants that enrolled in the 2007 survey cycle, Panel 3, include approximately 43,400 participants. The total cohort is over 152,000 members and will be adding approximately 60,000 U.S. military members, both active

duty and Reserve and National Guard, as well as a Millennium Cohort Family Study component of approximately 10,000 spouses later this year.

The cohort is based on a random sample of U.S. service members residing in all 50 states and territories; no selection or stratification is based on geographic location. Service members are often assigned and deployed to many geographic locations outside of the United States. Team members are working with professionals at Defense Manpower Data Center (DMDC) and U.S. Army Center for Health Promotion and Preventive Medicine (USA-CHPPM) to differentiate location of deployment and will include whatever data are available in these analyses. Basic geographic information, including duty and home address for all participants, is included.

Women were oversampled in Panels 1, 2, and 3. In Panel 2, to achieve a higher proportion of Marines, the population was comprised of 20% Marines and 80% other service branches (Army, Navy, Air Force, and Coast Guard). Different races/ethnicities have not been oversampled in any panel.

The mean age for Panel 1 at baseline is 35 years, Panel 2 is 24 years, and Panel 3 is 24 years, with an average age of 27.6 years for all 3 panels at baseline.

More than 70% of cohort members who submitted baseline data have submitted at least one follow-up questionnaire.

Approximately 88% of participants completed the questionnaire via the online questionnaire in the 2007 survey cycle.

Frequency of Data Collection: All panels will be followed with repeat surveys at 3-year intervals through 2022.

Source of Data: The Millennium Cohort Study is a research platform that prospectively combines self-reported data with inpatient, outpatient, pharmacy, vaccination, personnel, deployment, and occupational data.

Multiple standardized instruments (to compare to other civilian and veteran populations) are included in the questionnaire, including the posttraumatic stress disorder (PTSD) Checklist Civilian Version; the Patient Health Questionnaire to assess depression, panic, anxiety, eating disorders, and alcohol-related problems; the Medical Outcome Study Short Form 36-Item Health Survey for Veterans to assess functional health; and the CAGE questionnaire to assess potential problem drinking.

Mode of Data Collection: Participants are given the option to complete a web or paper survey.

Specific Questions Related to CVD, COPD, Asthma, and/or Diabetes: The Millennium Cohort Study baseline survey asks the following related questions:

- "Has your doctor or other health professional ever told you that you have any of the following conditions?"
  - — Hypertension, high cholesterol requiring medication, coronary heart disease, heart attack, angina (chest pain), any other heart condition: please specify, chronic bronchitis, emphysema, asthma, diabetes or sugar diabetes
- If marking yes to any of these conditions the participant is asked what year they were first diagnosed and if they were ever hospitalized for the condition.
- Other questions on the survey instrument relating to cardiovascular disease, chronic pulmonary disease, asthma, and/or diabetes include:
  - — "In the last 12 months have you had persistent or recurring problems with the following?" Shortness of breath, chest pain
  - — "During the last 4 weeks, how much have you been bothered by any of the following problems?" Shortness of breath, chest pain
  - — "Have you ever been diagnosed with gestational diabetes by a glucose tolerance test during pregnancy?"

Information Obtained: Research published in the November 2009 issue of *Hypertension* investigating the association between deployment and newly reported hypertension found that deployers who reported multiple combat exposures, especially those who personally witnessed death due to war or disaster, were at higher risk for newly reported hypertension, possibly indicating a stress-induced hypertensive effect.

Research findings published in the December 2009 issue of the *American Journal of Epidemiology* highlighted the first prospective population-based study to include changes in smoking as a covariate for investigation of increased risk for respiratory symptoms, asthma, bronchitis, and emphysema. This study suggested an elevated risk for respiratory symptoms, including persistent and recurring cough and shortness of breath, among Army and Marine Corps personnel deployed in support of the operations in Iraq and Afghanistan.

Follow-up of at-risk populations will allow for better understanding of the potential episodic nature of potentially acute and transient or early stages of chronic respiratory and cardiovascular illnesses.

Demographic data such as age, geographic home of record, and race/ethnicity are collected through the Defense Manpower Data Center. Income, education level, marital status, and military occupation are all asked on the 2010 Millennium Cohort Study survey.

Who Pays for Data Collection?: The Millennium Cohort Study is funded by the DOD through the U.S. Army Medical Research Materiel Command (USAMRMC) Military Operational Medicine Research Program (MOMRP) and conducted at the Naval Health Research Center (NHRC).

Dissemination of Data: The Millennium Cohort Study team has published over 30 manuscripts in notable peer-reviewed journals, produced greater than 150 conference presentations and posters since 2001, and has received multiple research awards at notable public health conferences.

Findings from the Millennium Cohort Study have been regularly presented to various organizations within the Department of Defense, as well as leading scientific institutions that advise military leaders and policy makers.

Additionally, several press outlets, including Reuters Online, the Atlanta Journal Constitution, Forbes.com, and the Defense Military Health System, featured articles on the study's research.

The Millennium Cohort Study surveys are available online to participants during survey cycles. Participants can gain access to the survey by logging-in with their assigned subject ID number and the last four digits of their Social Security number.

In order to protect participants' privacy and within rules governing human subjects research, identifiable data are not shared outside of the NHRC. Collaborations are encouraged and current collaborations exist with many external DOD, VA, academic, and other civilian institutions. Establishment of a memorandum of understanding or other data use agreement and support from one or more Millennium Cohort Study co-investigators must be obtained before data transfer of de-identified data can take place, though collaboration on various projects where data are not transferred is easily accomplished by outside researchers.

Multi-Ethnic Study of Atherosclerosis (MESA)

Main Purpose of Study: The Multi-Ethnic Study of Atherosclerosis was initiated in July 2000 to investigate the prevalence, correlates, and progression of subclinical cardiovascular disease (CVD) in a population-based sample (Bild et al., 2002). The objectives of MESA are (1) to determine characteristics related to progression of subclinical CVD to clinical CVD; (2) to determine characteristics related to progression of subclinical CVD itself; (3) to assess ethnic, age, and sex differences in subclinical disease prevalence, risk of progression, and rates of clinical CVD; (4) to determine relations of newly identified factors with subclinical disease and to determine their incremental predictive value over established risk factors; and (5) to develop methods, suitable for application in future screening and intervention studies, for characterizing risk among asymptomatic persons.

Sample: 6,500 men and women from six regions in the United States: Baltimore City and Baltimore County, Maryland; Chicago, Illinois; Forsyth County, North Carolina; Los Angeles County, California; New York, New York; St. Paul, Minnesota; Approximately 1,083 eligible participants per site (Bild et al., 2002). Minorities are not oversampled. Age range is 45–84, and includes men and women.

Response Rate: MESA Exam 1: Among those households contacted, recruiters explained the study to 29.0%, and among those, the participation rate was 39.8%. Among those screened and deemed eligible, the participation rate was 59.8% (from MESA study website).

Frequency of Collection and Sources of Data: Examination 1 (July 2000–July 2002); Examination 2 (July 2002–January 2004); Examination 3 (January 2004–July 2005); Examination 4 (July 2005–July 2007).

Sources of data include blood samples, medical exam records, and interviews

Mode of Data Collection: Medical exam, physical exam, laboratory exam, personal interview.

Specific Questions Related to CVD, COPD, Asthma, and/or Diabetes: Baseline measurements will include measurement of coronary calcium using computed tomography; measurement of ventricular mass and function using cardiac magnetic resonance imaging; measurement of flow-mediated brachial artery endothelial vasodilation, carotid intimal-medial wall thickness, and distensibility of the carotid arteries using ultrasonography; measurement

of peripheral vascular disease using ankle and brachial blood pressures; electrocardiography; and standard CVD risk factors; blood samples; identification and characterization of CVD events, including acute myocardial infarction and other coronary heart disease, stroke, peripheral vascular disease, and congestive heart failure; therapeutic interventions for CVD; and mortality (Bild et al., 2002).

Information Obtained: Prevalence, anthropometry, blood pressure, personal history, diet assessment medical history. Whether it includes clinical care age, race/ethnicity, geographic region, sex.

Who Pays for Data Collection?: National Heart, Lung, and Blood Institute (NHLBI) and the National Institutes of Health (NIH).

National Longitudinal Study of Adolescent Health (Add Health)

Main Purpose of Study: The National Longitudinal Study of Adolescent Health (Add Health) is a study of a nationally representative sample of more than 20,000 individuals that began with in-school questionnaires administered to adolescents in grades 7–12 in the United States during the 1994–1995 school year. Since then, four additional waves of in-home interviews in 1995, 1996, 2001–2002, and 2008 have been conducted, tracking the initial cohort as they transitioned out of adolescence into young adulthood and adulthood.

Add Health combines longitudinal survey data on respondents' social, economic, psychological, and physical well-being with contextual data on the family, neighborhood, community, school, friendships, peer groups, and romantic relationships, providing unique opportunities to study how social environments and behaviors in adolescence are linked to health and achievement outcomes in young adulthood. The later waves of interviews expanded the collection of biological data in Add Health to understand the social, behavioral, and biological linkages in health trajectories as the Add Health cohort ages through adulthood.

Add Health was developed in response to a mandate from the U.S. Congress to fund a study of adolescent health. The original purpose of the study was to examine adolescent health and health behavior with special emphasis on the effects of multiple contexts of adolescent health. As participants aged into adulthood, however, the scientific goals of the study expanded and evolved.

Waves I and II, conducted when respondents were between 12 and 18 years old, focus on the forces that may influence adolescents' health and risk behaviors, including personal traits, families, friendships, romantic relationships, peer groups, schools, neighborhoods, and communities.

Wave III, conducted when respondents were between 18 and 26 years old, focuses on how adolescent experiences and behaviors are related to decisions, behavior, and health outcomes in the transition to adulthood. Specific aims of Wave III included obtaining relationship, marital, childbearing, and educational histories, and dating key labor force events.

Wave IV, the most recent follow-up, was conducted when respondents were between 24 and 32 years old and assuming adult roles and responsibilities. The fourth wave of interviews focused on obesity, stress, and health risk behaviors and expanded the collection of biological data in Add Health to better understand genetic, stress, and pre-disease pathways.

Sample Size and Sample for Each Wave

- Wave I, Stage 1. 90,118 Adolescent In-School Questionnaires, 164 School Administrator Questionnaires, 20,745 Adolescent In-Home Interviews, 17,669 Parent Questionnaires (parent specific component), 17,713 Parent Questionnaires (child specific component)
  - — A stratified, random sample of all high schools in the United States was undertaken. A school was eligible for the sample if it included an 11th grade and had a minimum enrollment of 30 students. A feeder school—a school that sent graduates to the high school and that included a 7th grade—was also recruited from the community.
  - — A sample of 80 high schools and 52 middle schools from the United States was selected with unequal probability of selection. Incorporating systematic sampling methods and implicit stratification into the Add Health study design ensured that this sample is representative of U.S. schools with respect to region of country, urbanicity, school size, school type, and ethnicity.

- Wave I, Stage 2
  - — An in-home sample of 27,000 adolescents was drawn consisting of a core sample from each community plus selected special oversamples. Eligibility for oversamples was determined by an adolescent's responses on the In-School Questionnaire. Adolescents could qualify for more than one sample. In addition, parents were asked to complete a questionnaire about family and relationships.
- Wave II: 128 School Administrator Questionnaires, 14,738 Adolescent In-Home Interviews
  - — The Wave II in-home interview sample is the same as the Wave I in-home interview sample, with a few exceptions: the majority of 12th-grade respondents were removed from the Wave II sample, as they exceeded the grade eligibility requirement; the Wave I disabled sample was not reinterviewed at Wave II; the Wave II sample contains a small number of adolescents who did not participate in the first wave; and no parent interview was conducted at Wave II.
  - — In addition, school administrators were contacted by telephone to update school information. Information about neighborhoods/communities was gathered from a variety of previously published databases.
- Wave III: 15,197 Young Adult In-Home Interviews and biomarker collection
  - — The in-home Wave III sample consists of Wave I respondents who could be located and reinterviewed six years later. A sample of 1,507 partners of original respondents was also interviewed. Wave III also collected High School Transcript Release Forms as well as samples of urine (for sexually transmitted infections) and saliva (for HIV testing and, for full siblings and twins, DNA extraction).
- Wave IV: 15,701 Adult In-Home Interviews and biomarker collection
  - — All original Wave I in-home respondents were eligible for in-home interviews at Wave IV. Wave IV also included collection of blood pressure readings, anthropometric measures (height, weight, and waist circumference), saliva for DNA, and blood spots from a fingerstick from all consenting respondents. To estimate the reliability of biological measures in the Add Health population, anthropometric measures and collection of biospecimens on 100 Wave IV respondents were repeated.

Minorities Are Oversampled: Adolescents of Chinese, Cuban, Puerto Rican descent, and Blacks from well-educated families were oversampled (see below). Eligibility for oversamples was determined by an adolescent's responses on the In-School Questionnaire. Adolescents could qualify for more than one sample. Blacks from well-educated families—1,038 black adolescents with at least one parent with a college degree. Chinese—334 adolescents. Cuban—450 adolescents. Puerto Rican—437 adolescents

Age Groups Included: Wave I—Adolescents in grades 7–12 during the 1994–1995 school year. Wave II—Adolescents in grades 8–12 during the 1995–1996 school year. Wave III—Young adults age 18 to 26 years old. Wave IV—Adults age 24 to 32 years old.

Men and women are represented in the study in approximately equal proportions.

Response Rate: Wave I—78.9%. Wave II—88.2%. Wave III—77.4%. Wave IV—80.3%

Source of Data: The primary sources of data collection for Add Health are personal interviews, physical examinations, administrative records (e.g., high school transcripts), and publicly accessible databases (e.g., for information about neighborhoods and communities).

Mode of Data Collection: The primary modes of data collection for Add Health are in-school questionnaires (study participants), mailed questionnaires (school administrators), in-home personal interviews (study participants and their parents, siblings, and romantic partners), in-home biospecimen collection (study participants), and records abstraction.

Specific Questions Related to CVD, COPD, Asthma, and/or Diabetes:

Wave III

- Has a doctor ever told you that you have high cholesterol?
- Have you ever been diagnosed with high blood pressure or hypertension?
- Have you ever been diagnosed with diabetes?
- Have you ever been diagnosed with asthma?

Wave IV

- Has a doctor, nurse, or other health care provider ever told you that you have or had: high blood cholesterol or triglycerides or lipids?

- How old were you when the doctor, nurse, or other health practitioner diagnosed you with high blood cholesterol or triglycerides or lipids?
- Has a doctor, nurse, or other health care provider ever told you that you have or had: high blood pressure or hypertension (if female add, when you were not pregnant)?
- How old were you when the doctor, nurse, or other health practitioner diagnosed you with blood pressure or hypertension?
- Has a doctor, nurse, or other health care provider ever told you that you have or had: high blood sugar or diabetes (if female add, when you were not pregnant)?
- How old were you when the doctor, nurse, or other health practitioner diagnosed you with high blood sugar or diabetes?
- Has a doctor, nurse, or other health care provider ever told you that you have or had: heart disease?
- How old were you when the doctor, nurse, or other health practitioner diagnosed you with heart disease?
- Has a doctor, nurse, or other health care provider ever told you that you have or had: asthma, chronic bronchitis, or emphysema?
- How old were you when the doctor, nurse, or other health practitioner diagnosed you with asthma, chronic bronchitis, or emphysema?

Height and weight were also measured at Waves II and III, and DNA was collected from a subset of respondents at Wave III. In addition, Wave IV respondents were asked to participate in an inventory of all prescription medications they had used in the four weeks prior to the interview, anthropometric measures, blood pressure and pulse readings, collection of dried blood spots obtained from a finger prick, and collection of saliva for buccal cell DNA.

Information Obtained:

- Self-reported health history (Waves III and IV)
- Prescription medication inventory (Wave IV)
- Measured height (Waves II, III, and IV)
- Measured weight (Waves II, III, and IV)
- Calculated BMI (Waves II, III, and IV)
- Waist circumference (Wave IV)
- Arm circumference (Wave IV)
- SBP (Wave IV)
- DBP (Wave IV)
- Pulse (Wave IV)
- Pulse pressure (Wave IV)
- Mean arterial pressure (Wave IV)
- Metabolic measures (Wave IV)
- Inflammatory measures/high sensitivity C-reactive protein (Wave IV)
- Immune measures/Epstein-Barr virus antibodies (Wave IV)
- Candidate-gene and genome-wide genetic measures (Waves III and IV)
- Incidence data for high cholesterol, hypertension, diabetes, and asthma are available for all respondents who provided self-reported health history information at Waves III and IV.
- Prevalence data were captured through self-reported health histories at Wave III, and through self-reported health histories, a prescription drug inventory, and biological measures (anthropometric, cardiovascular, metabolic, inflammatory, immune, and genetic) at Wave IV.
- Functional health outcomes from the Add Health dataset include:
  - Respondent's participation in various types of physical activity
  - How much the respondent's health limits him/her in a range of activities
  - Whether the limitation in activities is caused by a condition that has lasted more than a year, or a condition that has developed recently
  - Whether the respondent uses a brace, cane, wheelchair, or other device because of a physical condition
  - How often a health problem has caused the respondent to miss a day of school or work

Risk Factors, Including Stressors: By combining longitudinal social, behavioral, and environmental data with new biological data, Wave IV greatly expanded the breadth of research questions that can be addressed in Add Health regarding pre-disease pathways, gene-environment interactions, the relationship between personal ties and health, factors that contribute to resilience and wellness, and environmental sources of health disparities.

The following are examples of risk factors and stressors available for analysis in Add Health: Hypertension, Diabetes, Hyperlipidemia, Genetic risk factors, Tobacco use, Alcohol and drug abuse, Obesity, Frequent intake of fast food and sweetened drinks, Low level of physical activity, Depression, Perceived stress, Personality factors, Poor mastery, Weak friendship ties, Religiosity factors, Poor sleep quality, Mental and physical job stress, Poor job satisfaction, Unemployment, Military combat experience, PTSD, Low respondent and/or parent education, Low respondent and/or parent income, Receipt of public assistance by respondent and/or parent, Lack of insurance, Lack of access to health care, Poor school quality, Homelessness, Disability, Poor relationship with parents, Foster care, Parental incarceration, Marriage dissatisfaction, separation and divorce, Unwanted pregnancies, Fertility problems, Parenting stress and single parenting, Child diagnosed with severe disease or chronic condition, Abuse and/or neglect by parent or partner, Victimization (i.e., witnessed violence, victim of physical or sexual assault), Criminal offending, involvement with the criminal justice system, and incarceration, Friend or family suicide, Death of parent, spouse, sibling, or child, Unsafe school, Unsafe living environment, Neighborhood/community crime, Neighborhood/community unemployment, Poor access to public parks and physical activity resources, Unfavorable community climate and weather, Unfavorable social policies and programs.

Clinical Care Information: Health insurance coverage, Access to health services, Length of time since last routine checkup, Length of time since last dental exam, Psychological or emotional counseling in the past 12 months

Demographic Characteristics Collected: Age, Sex, Race/ethnicity, Geographic region, Citizenship, Primary language, Languages spoken/written, Income, Education level, Occupation, Military status, Health insurance status, Family size/structure, Religious affiliation, Sexual orientation.

Who Pays for Data Collection?: The Add Health Study is funded by 24 Federal agencies and foundations:

- Eunice Kennedy Shriver National Institute of Child Health and Human Development
- MacArthur Foundation
- National Cancer Institute
- National Center for Health Statistics, Centers for Disease Control and Prevention, HHS
- National Center for Injury Prevention and Control, Centers for Disease Control and Prevention, HHS
- National Center for Minority Health and Health Disparities
- National Institute of Allergy and Infectious Diseases
- National Institute of Deafness and Other Communication Disorders
- National Institute of General Medical Sciences
- National Institute of Mental Health
- National Institute of Nursing Research
- National Institute on Aging
- National Institute on Alcohol Abuse and Alcoholism
- National Institute on Drug Abuse
- National Science Foundation
- Office of AIDS Research, NIH
- Office of Behavioral and Social Sciences Research, NIH
- Office of Minority Health, Centers for Disease Control and Prevention, HHS
- Office of Minority Health, Office of Public Health and Science, HHS
- Office of Population Affairs, HHS
- Office of Research on Women's Health, NIH
- Office of the Assistant Secretary for Planning and Evaluation, HHS
- Office of the Director, NIH
- Robert Wood Johnson Foundation

Dissemination of Data: Data from all waves of the Add Health study are disseminated by the Inter-University Consortium for Political and Social Research (ICPSR) as a part of their Data Sharing for Demographic Research

(DSDR) project. The DSDR Add Health webpage contains the Add Health study description, publications list, documentation files, and data sets for analysis: http://www.icpsr.umich.edu/cocoon/DSDR/STUDY/21600.xml.

The Add Health data are available in two forms—public-use data sets and restricted-use contractual data sets. The public-use data sets contain data on only a subset of respondents (to protect the confidentiality of study respondents). The public-use data sets are available to any researcher and may be obtained from either DSDR (at no charge) or Sociometrics (for a fee). The restricted-use contractual data sets contain more extensive data and are distributed by DSDR to certified researchers who commit themselves to maintaining limited access. To be eligible to enter into a contract, researchers must have an IRB-approved security plan for handling and storing sensitive data and sign a data-use contract agreeing to keep the data confidential.

The Add Health public-use data are currently available for download from the DSDR website. To download the data, users must create an online personal account. The system uses an email address as a login ID and requires a password.

The Add Health restricted-use contractual data will be available for download from the DSDR website in Summer 2010. Restricted-use data will be available to certified researchers who sign an online restricted-use data agreement.

Through its Data Sharing for Demographic Research project, ICPSR supports a system for analyzing the Add Health public-use data online. The online analysis system allows users to run both simple and complex analyses, recode and compute new variables, and download subset variables or cases. To access the online analysis system, users must create an online personal account.

Olmstead County Study

Main Purpose of Study: Olmstead County Study includes two cohorts on coronary heart disease (CHD) and heart failure (HF) respectively. The CHD cohort examines the incidence of and survival after ACS (MI and UA) in a geographically defined population; prospectively characterizes the case mix and outcome of ACS in the population; and prospectively examines the value of novel biomarkers for risk prediction in ACS in the population. The HF cohort examines the incidence of all-cause and HF-specific hospitalizations after HF diagnosis (both in- and outpatient cases) in a geographically defined incidence cohort of persons with validated HF identified between 1979 and present; prospectively examines the incidence and total number of hospitalizations according to the type of HF (EF and diastolic function); and prospectively measure health status using a generic (SF-12) and disease specific (KCCQ) instrument to examine the association between health status and hospitalizations.

Sample: CHD cohort: 4,059 incident cases of MI, including both prospective and retrospective cohorts; HF cohort: 3,386 cases, including both prospective and retrospective cohorts.

Men and women age 18 and above residing in Olmstead County, Minnesota, were eligible for the study. Minorities were not oversampled. The response rate for the CHD cohort, prospective component was 82%, retrospective component 97%; and for the HF cohort, prospective component 67%, retrospective component 97%.

Sources of Data: Medical records—the Rochester Epidemiology Project (REP) indexes and links medical records from all sources of care for Olmsted County residents; Informed consent—Questionnaires and biobanking

Mode of Data Collection: Medical record data abstraction by a nurse; questionnaires and biobanking

Specific Questions Related to CVD, COPD, Asthma, and/or Diabetes: cardiovascular risk factors and comorbidities

Information Obtained: Incidence; some functional health outcomes for Heart Failure; risk factors that include diabetes, hypertension, hyperlipidemia, and body mass index; comorbidities, including malignancies, cerebrovascular disease, and liver disease; detailed clinical care information on medications, labs, and procedures; demographic information including age, sex, race, ethnicity, education, marital status, income level.

Cost: CHD: $4,047,519 (1/1998-5/2010); HF: $3,495,062 (1/2003-6/2010)

Who Pays for Data Collection?: CHD: NIH grant—RO1HL59025; HF: NIH grant—RO1HL72435

Dissemination of Data: Data sharing is contingent upon appropriate compliance with HIPAA regulations. Specifically, on a case-by-case basis, "limited data sets" as defined by the U.S. Department of Health and Human Services can be released to qualified investigators who have obtained approval from all appropriate IRBs. *Comment:* Case ascertainment: CHD: ARIC criteria; HF: Framingham criteria; Study design: CHD: retrospective—medical

records abstraction; HF: prospective—informed consent with questionnaires and biobanking; Data disseminated through publications.

Rancho-Bernardo Study

Main Purpose of Study: The Rancho Bernardo study examines the prevalence of heart disease risk factors and follow-up for common chronic diseases.

Sample: Includes approximately 6,000 men and women aged 30 years and above in a suburb of San Diego. Minorities are not oversampled. The Racho-Bernardo Study is a census-based geographically defined "new town" study. Baseline evaluation took place between 1972–1974, and the most recent 2007–2010. The majority of evaluations were limited to those aged 50 and above at the time of visit. The response rate was 82% of baseline.

Frequency of Collection and Sources of Data: Annual mailer for vital status; Clinical evaluations every 2–4 years depending on funding. Population interviews; physical examination; blood tests; hospital validation of selected diseases

Mode of Data Collection: Annual mailer and periodic in-clinic evaluation

Specific Questions Related to CVD, COPD, Asthma, and/or Diabetes: Has a doctor ever told you that you have had a heart attack, heart failure, angina, stroke, TIA, coronary artery revascularization, diabetes, emphysema, asthma? Rose angina and claudication questionnaire, family history of cardiovascular disease, diabetes, and premature mortality; lifestyle including diet, smoking, alcohol, physical activity, and current medication use.

Information Obtained: Incidence data on CVD, diabetes, death, death certificates coded by nosologist. Prevalence of all common diseases. Functional health outcomes: Instrumental Activities of Daily Living (IADL), Activities of Daily Living (ADL), SF-36 or SF-12 on 3 occasions, ability to walk unaided, balance, chair stand, grip strength, pulse rate, spirometry, cognitive function tests. Risk factors: blood pressure, height, weight, waist girth, pulse rate; Stress, happiness, QWB.

Clinical care information includes blood tested for cholesterol, triglycerides, HDL, CRP-IL-6, fasting and post-challenge glucose, liver and kidney function tests, other biomarkers, ECGs; Selected diseases information validated from hospital records. Demographic information: age, race/ethnicity, geographic region, income, education level, occupation, health insurance status, frequency of health care visits, hospitalizations, surgeries

Who Pays for Data Collection?: NIH grants from various institutes; extramural study

Dissemination of Data: Any legitimate investigator can collaborate; Sometimes data are sent to a small group.

This is the longest running extramural study of aging with good diabetes data and OGTT. Diabetes (as a disease and as a CHD risk factor) has been primary focus since inception. More than 400 publications, and countless junior faculty, students, and visiting scholars have worked with these data. The study has a biobank for biomarkers, including hormones, adipocytokines, etc., and has measured another 40 markers from this cohort awaiting analysis. There are also small studies of Filipinos and African Americans—about 400 each, using the same protocol for race/ethnicity studies focused on diabetes and CVD risk factors. The study have measures of subclinical CVD including ankle-brachial index for lower extremity arterial disease, carotid ultrasound, and coronary artery calcium. Share data for meta-analyses regularly (participated in about 10), mostly from collaborative study groups at Oxford and Cambridge, UK; Unable to afford Medicare data.

Strong Heart Study (SHS)

Main Purpose of Study: The main purpose is to determine the prevalence and incidence of cardiovascular disease (CVD) and its risk factors in American Indians, and to identify important CVD risk factors in this population.

Sample: Initial cohort: 4,549 (since 1989); Family cohort (Strong Heart Family Study or SHFS): 3,838 from 94 families (since 2001). The sample is approximately evenly distributed among the three sites: Arizona (AZ), North/South Dakota (DK), and Oklahoma (OK). All participants are American Indians. Age groups included: Initial cohort: 45–74 years, Family cohort: $\geq$ 15 years. Both men and women are included. The response rate for the initial cohort was 62% of the total population aged 45–74 years.

Frequency of Data Collection: Approximately every four years since 1989.

Source of Data: Personal interviews, physical exams, medical records, and hospital discharges.

Mode of Data Collection: In-person exams and interviews and medical record abstraction.

Specific Questions Related to CVD, COPD, Asthma, and/or Diabetes: Many questions and procedures (including ECG, echocardiogram, Carotid ultrasound, pulmonary function testing, fasting glucose, and insulin measurements).

Information Obtained: Incidence, prevalence, functional health outcomes, risk factors (including stressors), limited clinical care information, and demographic characteristics (participants are covered by Indian Health Service)

Who Pays for Data Collection?: NHLBI/NIH

Dissemination of Data: At this time, data are available only to investigators who have a paper that has been approved by the SHS Publications and Presentations Committee or who have an ancillary study that has been approved by the SHS Steering Committee.

REGISTRIES

Cardiac Arrest Registry to Enhance Survival (CARES) Registry

Main Purpose of Study: CARES is a quality improvement registry to help local EMS administrators and medical directors identify when and where cardiac arrest occurs, which elements of their EMS system are functioning properly in dealing with these cases, and what changes can be made to improve outcomes. The ultimate goal of CARES is to help local EMS administrators and medical directors identify the populations affected by out-of-hospital cardiac arrests as well as when and where these arrests occur, to identify the elements of the system that are functioning properly and those that are not, and to provide information on how to affect systems changes to improve cardiac arrest outcomes. Geographic region information may be obtained by the CARES program managers through data reporting.

Sample: As of March 2010, there are CARES sites in approximately 40 communities in 23 states and the District of Columbia. Communities are located in each region of the United States (East Coast, West Coast, Central, Hawaii, and Alaska). Sites include communities at the county level, city level, state level, and work with two non-U.S. countries. CARES uses a Utstein style of statistics to identify and track cases of out-of-hospital cardiac arrest in defined geographical areas. CARES includes both men and women 18 years or older. Minorities are not oversampled.

Frequency of Data Collection: CARES uses a secure web-based system in which event information is entered directly by the participating sites as the events occur.

Sources of Data: EMS agencies, hospitals, computer-aided dispatch systems

Mode of Data Collection: Completion of the CARES form, direct entry into the website database, or exporting electronic data form field software programs

Specific Questions Related to CVD, COPD, Asthma, and/or Diabetes: The registry is designed specifically for out-of-hospital cardiac arrest and asks questions that deal with the cardiac event such as location of the arrest, whether the arrest was witnessed or not, presumed etiology of the arrest and associated resuscitation attempt information, and arrest rhythms.

Information Obtained: The clinical care information covers the care the patient received from the EMS providers prior to arrival at the hospital. The demographic characteristics collected are age, race/ethnicity, and gender by the individual sites.

Who Pays for Data Collection?: The Centers for Disease Control and Prevention provides funding to Emory University to develop and implement the CARES program. Historically, the CDC has provided between $300,000 and $500,000 annually to the program. The participating sites are not charged a fee to join the registry. The CDC provides the funding annually to the program for operational assistance. None of the sites pays into the program for participation.

Dissemination of Data: All the data are online on a protected web server. Data are made available to the CDC for reporting as part of CDC's National CVD Surveillance System. The CARES website has both a password protected area and a public area where information may be found about the program.

The participating sites have access to reporting functions that provide performance benchmarking information but not access to any identifiable information. Access is granted through the program managers and is usually provided only to sites who participate in the registry.

Cardiovascular Research Network (CVRN): The HMO Research Network (HMORN)

Main Purpose of Study: To evaluate the epidemiology, quality of care, and outcomes of cardiovascular disease and to conduct future clinical trials using a community-based mode (Go et al., 2008). CVRN's overall goals are to provide more robust CVD and related healthcare surveillance data than are currently available; promote research on clinical practice and quality of care; enable assessment of new diagnostic and therapeutic technologies and clinical guidelines on CVD and risk factor incidence, prevalence, clinical management, and patient outcomes over time; facilitate research on determinants of disease for uncommon disease phenotypes; and create opportunities for interested non-network researchers to collaborate with CVRN investigators on high-priority cardiovascular issues. Participants include the HMO Research Network (HMORN) is a consortium of 15 U.S. healthcare delivery systems. HMORN's primary goal is to transform healthcare practice through population-based research to improve the health and health care of broad populations. HMORN accomplishes this by fostering research collaborations; enhancing awareness of research interests, resources, and capabilities of the member research centers; sharing methodologies, best practices, and consultative expertise; and leveraging the HMORN's strengths (http://www.hmoresearchnetwork.org/resources/tools/HMORN_Brochure.pdf).

Sample: More than 11 million U.S. citizens; 15 research centers, including the Center for Health Services Research, Detroit, Michigan, Henry Ford Health System, Health Alliance Plan; Department of Research and Evaluation, Pasadena, California, Kaiser Permanente Southern California; Geisinger Center for Health Research, Danville, Pennsylvania, Geisinger Health System; Group Health Research Institute, Seattle, Washington, Group Health Cooperative; Harvard Medical School Department of Ambulatory Care & Prevention, Boston, Massachusetts, Harvard Pilgrim Health Care; HealthPartners Research Foundation, Minneapolis, Minnesota, HealthPartners; Kaiser Division of Research, Oakland, California, Kaiser Permanente Northern California; Kaiser Institute for Health Research, Denver, Colorado, Kaiser Permanente Colorado; Lovelace Clinic Foundation, Albuquerque, New Mexico, Lovelace Health Systems; Marshfield Clinic Research Foundation, Marshfield, Wisconsin, Marshfield Clinic, Security Health Plan of Wisconsin; Meyers Primary Care Institute, Worcester, Massachusetts, Fallon Community Health Plan, Fallon Foundation, University of Massachusetts Medical School; Scott & White Health Care Division of Research, Temple, Texas, Scott & White Health Plan; The Center for Health Research—Northwest, Portland, Oregon, Kaiser Permanente Northwest; The Center for Health Research—Hawaii, Honolulu, Hawaii, Kaiser Permanente Hawaii; The Center for Health Research—Southeast, Atlanta, Georgia, Kaiser Permanente Georgia.

The sample includes men and women of all ages. Minorities are not oversampled. Retention rates of cohort from 2002 vary by CVRN site: 70–90% (1-year); 50–70% (3-year); 40–60% (5-year) (http://www.cvrn.org/info/retention.html).

Specific Questions Related to CVD, COPD, Asthma, and/or Diabetes: CVRN research studies: (1) Hypertension Recognition, Treatment, and Control in Community Practice evaluates three sites involving > 850,000 subjects with recognized and unrecognized hypertension; (2) Community-based Control and Persistence of Warfarin Therapy and Associated Rates and Predictors of Adverse Clinical Events in Atrial Fibrillation and Venous Thromboembolism evaluate quality of care and therapy risk across 5 sites; (3) Implantable Cardioverter Defibrillators for Primary Prevention in Community Practice—Clinical Characteristics, Outcomes, Resource utilization, and Cost; Additional funding to study longitudinal outcomes of patients receiving drug eluting stents, to assess risks and benefits of varying durations of clopidogrel therapy in patients receiving intracoronary stents and to assess the comparative effectiveness of second-line anti-hypertensive agents in patients whose blood pressure is not controlled on a thiazide diuretic alone.

Information Obtained: Administrative database—deaths; Clinical database—hospitalizations, emergency room, laboratory, long-term care, home health care, pharmacy, members with Rx benefit. Age, race, gender.

Who Pays for Data Collection?: Cardiovascular Research Network (CVRN) is a 5-year grant funded in 2007 by the National Heart, Lung, and Blood Institute (NHLBI).

Dissemination of Data: Data are not available online. The CVRN data network is guided by the creation and maintenance of a distributed architecture for data storage based on standardized data definitions; governance based on data holders' ability to opt in or out of individual activities; and transfer of the minimum amount of required data in order to maximize data security (Magid et al., 2008).

COPD Foundation Bronchiectasis Research Registry

Main Purpose of Study: The Bronchiectasis Research Registry is a consolidated database of non-cystic fibrosis (non-CF) bronchiectasis patients enrolled at multiple U.S.-based clinical institutions. The goal of the Bronchiectasis Research Registry is to support collaborative research and assist in the planning of multicenter clinical trials for the treatment of non-CF bronchiectasis, a progressive, non-curable disease of the lungs that afflicts thousands of patients. The registry will also be used to provide better insight into the diagnosis of the etiology of the different types of bronchiectasis, as well as the pathophysiology of the disorder.

Sample: There are currently 800 patients enrolled in this registry.

Patients are enrolled at 11 sites located throughout the United States. In process of completing and executing regulatory documents to allow three additional U.S.-based sites to join the consortium. The consortium will be expanding to include international sites in 2011. The participating centers enrolling patients are located across the United States. Minorities are not oversampled. All patients aged 18 years or older with a diagnosis of bronchiectasis who complete appropriate informed consent procedures are included. Confirmed diagnosis is defined as cough and/or daily or frequent mucopurulent phlegm plus chest imaging (X-ray or HRCT) showing dilated and thickened airways. Both men and women are encouraged to participate.

Frequency of Data Collection and Sources of Data: Data are collected at baseline visit and at annual follow-up visits. Data acquisition is carried out in one of two modes: (1) Medical records are reviewed and data are abstracted in order to complete the forms on patients seen in the past 3 years by a participating investigator and (2) Forms are completed during a clinical examination scheduled as part of patients' usual care during the study period, and/or through patient contact.

Mode of Data Collection: The DMS can be used either for electronic capture (EDC, with data recorded directly onscreen and validated during collection) or for distributed data management (with data recorded first on paper forms and then keyed and validated at the participating centers). Sites have the flexibility to select a data collection method that suits their needs. Up-to-date paper versions of each data collection instrument are available for situations in which the computer systems are not appropriate or are inaccessible for any reason.

Specific Questions Related to CVD, COPD, Asthma, and/or Diabetes: Data collection includes personal contact information (provided consent has been provided); demographic characteristics; medical history; and clinical procedures relative to the treatment of bronchiectasis, namely, respiratory symptoms, pulmonary function testing, HRCT parameters, diagnostic tests, and therapies.

Information Obtained: Incidence, prevalence, functional health outcomes, risk factors, including stressors, clinical care information, and demographic characteristics.

Cost of Registry: It costs approximately $200,000 a year to maintain the registry and pay sites for enrolling and following up patients.

Who pays for Data Collection: The COPD Foundation and the Richard H. Scarborough Fund as well as industry partners provide funding for the registry including data collection.

Dissemination of Data: A web-based data management system (DMS) is used for the Bronchiectasis Research Registry. The data management system provides all of the capabilities required for research data management, including: data entry, data transfer, data validation, database updating, database closure, data retrieval, data entry, security and confidentiality, and archiving. The server and registry database reside at the coordinating center.

As an alternative to keying data, the system can accept data files that are transferred into the database via a

batch process. The system can accept Excel files, Access tables, delimited ASCII files, or other standard formats. Reading center and laboratory data are often loaded with this process.

Data files are available online. As part of the registry program, each consortium member has the ability to generate a variety of reports and data queries (for reports) through the Interactive Reporting System. This system is web-based and provides an attractive and powerful interface that supports several types of information requests. Features of the interface are based on usage scenarios provided by the consortium membership and include standard reports and freeform queries. Examples of standard reports include frequency distributions of registry participants by demographic variables, cross-tabulations of two or more clinical indexes, and descriptive summaries of lung function parameters. Statistical analysis is supported by the interface to a level of sophistication determined by data appropriateness and usage scenarios. For categorical variables, the focus is on cross-tabulations and measures of association. Means, medians, standard deviations, and minimum and maximum values are generated for continuous variables. Distributions of both categorical and continuous variables can be requested for all patients in the registry database, for only those patients consenting to be contacted about future studies, and for various demographic or clinical subgroups of patients. Consortium members can generate custom analyses through the use of pull-down menus and check-boxes for variable specification and coding. Statistical modeling is also available for a limited set of applications including linear and logistic regression modeling.

Each consortium member and staff at the University of North Carolina who work on the registry have access to the data. Data confidentiality and security are applied at all levels of data acquisition, transfer, and storage. The DMS developed by the University of North Carolina meets exacting data management standards of confidentiality, as well as HIPAA requirements. Access to the DMS requires two levels of identification, one to gain access to the CSCC server and one to gain access to the registry data management system. Users of the system are assigned job-specific permissions such as data entry, reporting, or query resolution. Confidential data collected from the sites are encrypted by the system and only decrypted for display on-screen by authorized users of the system. It is a requirement for all CSCC staff to complete a confidentiality certification procedure upon employment. Policies regarding the confidential nature of the data collected, processed, and stored at the UNC CSCC are explained to all personnel, who must then sign a "confidentiality certification" to be allowed access to confidential information.

COPD Foundation Research Registry

Main Purpose of Study: The COPD Foundation Research Registry is a confidential database of individuals diagnosed with COPD or at risk of developing COPD. The registry was established in 2007 by the COPD Foundation to help researchers learn more about COPD and to help people interested in COPD research find opportunities to participate. The COPD Foundation Research Registry serves as an avenue to collect, analyze, and disseminate data on the phenotypes, progressions, and possible treatments of COPD. The information contained in the registry, such as the clinical characteristics, will inform possible research hypotheses. The registry will also assist with the creation of therapeutic clinical trials by providing the information on the number of subjects available with specific inclusion/exclusion criteria as well as information on the symptoms and medication use by those subjects. The registry is a source of identifying subjects who may qualify for specific trials and who may be willing to be a participant in such a trial.

The specific aims of the COPD Foundation Research Registry are as follows: (1) Create and maintain a registry of up to 50,000 people with COPD or who are at risk for developing COPD that are willing to be contacted to ascertain their interest in participating in clinical research; (2) Use the registry as a source of possible subjects for the COPDGene® Study; (3) Use the registry as a source of possible subjects for future clinical research studies that require people with COPD or people who are at risk for developing COPD; and (4) Use the registry to determine demographic data and clinical characteristics of a broad cross section of people with COPD or at risk for developing COPD.

As stated in Aim 2 above, the COPD Foundation Research Registry is used as a means of helping to recruit patients for participation in the COPDGene® Study. Further information about the COPDGene® Study is contained earlier in this document.

Sample: Size of the COPD Foundation Research Registry: Currently, there are 3,000+ patients who have agreed to participate in the COPD Foundation Registry and be contacted for future participation in research studies. The foundation is continuing to advertise and market the registry to expand the cohort. It is currently looking at Pulmonary Rehabs as an additional avenue to recruit more patients for participation.

Patients enrolled in the registry are located throughout the country. Geographic levels include local, state, and national through subject ZIP codes. The majority of registry participants live in the United States. Anyone who is at least 18 years of age and diagnosed with COPD or who may be considered at risk of the development of COPD may participate. Both men and women are encouraged to participate in the registry. African Americans are a group for which minimal COPD information is available. The registry is helping to ensure that the African American population enrollment goal is met.

The COPD Foundation has many mechanisms to enable individuals to participate in the registry; for example, online submission, fax, and mail submission. It is difficult to assess the response rate given the various methods the foundation has implemented to enable individuals to participate. There are increases in enrollment after the registry is advertised and promoted in publications, when administrative or scientific leadership present and give talks/lectures and when the COPD Foundation exhibits at scientific or patient-related conferences.

Frequency of Data Collection and Sources of Data: Data are collected one time for each participant using the registry survey.

Source of Data: The COPD Foundation Research Registry is a patient reported database. As a result, subjects self-report their data using the registry survey.

Mode of Data Collection: Data are collected via a secure, online web-based survey or paper questionnaire/informed consent document. Patients may download the form and mail it to the Data Coordinating Center or they may request that a paper survey be mailed to their home. Data from web-based surveys are directly submitted into the database. For responses that are mailed, a data entry person inputs the data into the Registry.

Specific Questions Related to CVD, COPD, Asthma, and/or Diabetes: Specific questions regarding cardiovascular disease and diabetes are not asked. Specific questions related to chronic pulmonary disease are asked. Patients are asked what tests they have had performed (PFT or spirometry, Chest X-ray, Chest CT, or genetic blood test). Patients are asked about their lung symptoms, breathlessness, smoking history, medications, respiratory history, family history, exacerbations, and general demographic information.

Information Obtained: Incidence, prevalence, functional health outcomes, risk factors, including stressors, clinical care information, and demographic characteristics.

Cost of Registry: The COPD Foundation expends about $10,000–$15,000 annually for the maintenance and operation of the registry.

Who Pays for Data Collection?: The COPD Foundation pays for the data collection and the other costs associated with the creation and management of the registry.

Dissemination of Data: Data files are not available online, but patients may enroll and complete the form online. Per the registry's informed consent, only authorized staff at National Jewish Health may access the registry's data. A strict proposal review process, including required IRB approval/exemption documentation, is followed when an individual wishes to access the cohort. The process includes review by a committee that approves/disapproves proposals for access to the cohort. After the proposal has been vetted and approved, patients who are eligible for participation are contacted by the registry's Data Coordinating Center and the patients are informed that they qualify for participation in a specific research study. Patients are referred to the investigator for participation in the proposed study. It is the responsibility of the patient to contact the investigator. Investigators are never given patients' contact information

International Registry of Acute Aortic Dissection (IRAD)

Main Purpose of Study: Aortic dissection is the most common acute aortic condition requiring urgent surgical therapy (Hagan et al., 2000). The International Registry of Acute Aortic Dissection (IRAD), a consortium of research centers, enrolls patients at large referral centers to assess current presentation, management, and outcomes of acute aortic dissection (IRAD website, http://www.iradonline.org/irad.html). More specifically, the research

centers study everything from dates and times of symptom onset, presentation, diagnosis, hemodynamic signs of aortic dissection, initial and chronic medical therapy, to diagnostic imaging chosen, and surgical and medical management.

Sample: IRAD includes 24 large referral centers in 12 countries; data available on 1,600 acute aortic dissection cases (IRAD website, http://www.iradonline.org/irad.html). IRAD sites include University of Michigan Hospital, Washington University Hospital, Mayo Clinic, Minneapolis Heart Institute, University of Pennsylvania Hospital, Brigham & Women's Hospital, Massachusetts General Hospital, Duke University, St. Michael's Hospital (Canada), University of Tokyo Hospital (Japan), Tromsø University Hospital (Norway), Hospital Bichat (France), Robert-Bosch Krankenhaus (Germany), University of Rostock Hospital (Germany), Medical School Graz (Austria), University of Vienna Hospital (Austria), Hospital General Universitari Vall d'Hebron (Spain), Hospital General Universitario "12 de Octubre" (Spain), Cardiocentro Ticino (Switzerland), University Hospital S. Orsola (Italy), San Giovanni (Italy), and Hadassah University Hospital (Israel).

Sources of Data: Patient history, physical findings, imaging studies and outcomes; Physician review of hospital records

Mode of Data Collection: A questionnaire of 290 variables developed by IRAD investigators

Information Obtained: Clinical care: prior cardiac surgery: aortic valve placement, aortic aneurysm and/or dissection, coronary artery bypass graft surgery, mitral valve surgery; latrogenic: catheterization/PTCA, cardiac surgery; pain symptoms: any pain reported; syncope. Demographic information: age, gender, ethnicity.

Dissemination of Data: Data are not available online.

National Cardiovascular Data Registry (NCDR)

Main Purpose of Study: The NCDR provides evidence-based quality improvement solutions for cardiologists and other healthcare providers who are committed to measurement, improvement, and excellence in cardiovascular care. NCDR is comprised of over 2,200 hospitals involved in 5 hospital-based registries and more than 600 offices in our practice-based registry.

Sample: NCDR has participating hospitals from every state and participating practices from every state except Alaska. Benchmarking reports are compiled and presented at the national level. Current reports are at the national level. Beginning to look at the state level, especially in the ACTION Registry-GWTG to support STEMI care initiatives. Participating hospitals and practices are required to submit consecutive patients that meet the inclusion criteria for our registries. Oversampling is not necessary since a 100% sample of the patient population is captured.

Current population records include patients 18 years of age and older, both men and women. With the release of ICD V.2 (April 2010) and IMPACT (Winter 2010), NCDR will be gathering data on all age groups.

While response rates vary between registries, the NCDR enjoys a greater than 95% data submission success by its participants. Data submissions to NCDR are scheduled on a quarterly basis. Data collection is an ongoing process in our member facilities.

Sources of Data: The primary source of data is the hospital or practice medical record. Data collection varies among sites. In many cases, sites capture data concurrently via electronic interfaces with ADT and EMR systems. However, depending on the site's available technology, there are still many who collect data retrospectively via paper forms. The NCDR provides a web-based data collection tool as a part of registry participation. Irrespective of data collection processes, all data are sent via a secure, electronic submission process.

Specific Questions Related to CVD, COPD, Asthma, and/or Diabetes: All of these patient conditions are captured across our registries, with the exception of asthma. Cardiovascular disease, chronic pulmonary disease, and diabetes are collected across the registries; CathPCI Registry®: procedure-based registry collecting data on diagnostic and interventional caths; ICD Registry™: procedure-based registry collecting data on ICD implants and lead information for adult and pediatric patients; ACTION Registry®-GWTG™: process-based registry collecting data on STEMI and non-STEMI patients; CARE Registry®: procedure-based registry collecting data on carotid revascularization procedures (stenting and endarterectomy); IMPACT Registry™: procedure-based registry collecting data on patients with congenital heart disease (adult and pediatric); in a pilot phase, expected launch late

2010; PINNACLE Registry™: practice-based registry collecting data on patients and the care provided to them in the office setting. Particular focus is on coronary artery disease, hypertension, heart failure and atrial fibrillation.

Information Obtained: Incidence and prevalence data are collected. Functional health outcomes: NCDR collects 30-day follow-up in the CARE Registry and are involved with an ICD longitudinal study. Additional studies are being designed to capture functional status. Risk factors: NCDR collects medical risk factors but does not include stress-related data points. Clinical care information: metrics derived from the submitted data help to drive care improvements in member facilities. Demographic characteristics: the registry collects date of birth, race/ethnicity, health insurance status and sex.

Who Pays for Data Collection?: Annual membership fees are $4,000/year/registry with the exception of PINNACLE Registry and ACTION Registry-GWTG, which are no cost. Data collection staff are supplied by and paid for by the member hospitals or practice.

Dissemination of Data: Data files are available for member facilities through a secure, web-based portal. Data extract tools are available for participating members. A series of online query tools will be launched in 2011. Each participating site creates and maintains appropriate access levels for their designated staff/physicians. Access to the data is managed via a formal request process that is available to any interested party. Each registry has a Research and Publications Committee that assesses research requests for their applicability and feasibility.

NCDR supports robust research on the aggregated limited data it houses. Numerous health plans and state regulators require participation in one or more of its registries as part of their preferred provider program or certificate of need program. Additionally, NCDR is the only data collection option for meeting the CMS Primary Prevention coverage for ICDs. Data Quality: Sites submit data on a quarterly basis to the NCDR. The data are processed and assessed for data quality. The data quality report provides the participant with detailed summaries of the completeness for each data field. Participating sites access their data quality report via the web within minutes of their data submission.

Paul Coverdell National Acute Stroke Registry

Main Purpose of Study: Survey and improve the quality of acute stroke care from onset through hospital discharge

Sample: Hospital data in six states: Georgia, Massachusetts, Michigan, Minnesota, North Carolina, Ohio. Age group is ≥ 18 years of age. Men and women included. Response rate: Request all hospital admissions for acute ischemic stroke, hemorrhagic stroke, and TIA. Response rate varies from 45-100%.

Frequency of Data Collection and Sources of Data: Continuous; concurrent with care and retrospective. The source of data is hospital medical records.

Mode of Data Collection: Health department staff abstract data from hospital medical records.

Specific Questions Related to CVD, COPD, Asthma, and/or Diabetes: Medical history of stroke, TIA, myocardial infarction, diabetes, dyslipidemia, hypertension, atrial fibrillation, cardiac valve prosthesis, congestive heart failure, peripheral vascular disease, sickle cell disease, carotid stenosis, tobacco use; taking antihypertensive medication, taking lipid lowering medication; labs: LDL, HDL, total cholesterol, triglycerides, HbA1c; discharge destination.

Information Obtained: Ambulatory status pre- and post-event; in-hospital mortality; discharge destination; comfort measures status; treatment provided, complications (UTI, DVT/PE, pneumonia), dysphagia screening, smoking cessation counseling, 8 NQF endorsed stroke performance measures; arrival mode; place of occurrence; stroke unit care; neurology consult or care; CT results; principle ICD9 code; primary stroke ICD9 code; clinical diagnosis; stroke severity (Glasgow coma score or NIH Stroke Scale Score); clinical exam characteristics; age, race, Hispanic ethnicity, state, insurance status.

Cost of Registry and Who Pays for Data Collection: $600,000/year per state; includes quality improvement program, 5% data reabstraction; program evaluation. Centers for Disease Control and Prevention pays for the data collection.

Dissemination of Data: Key indicators are reported as part of CDC's National CVD Surveillance System.

SURVEYS

Behavioral Risk Factor Surveillance System (BRFSS)

Main Purpose of Study: The Behavioral Risk Factor Surveillance System (BRFSS), a state-based system of health surveys, collects information on health risk behaviors, preventive health practices, and healthcare access primarily related to chronic disease and injury. Across many states, BRFSS may be the only available source of timely, accurate data on health-related behaviors.

Sample: More than 350,000 adults are interviewed each year in the 50 states, District of Columbia, Puerto Rico, U.S. Virgin Islands, and Guam. Data are collected at the state, county, and city levels, with selected metropolitan and micropolitan statistical areas (MMSAs). BRFSS includes noninstitutionalized men and women aged 18 years and older.

Frequency of Collection and Sources of Data: The survey is done annually, and there is monthly state telephone surveillance.

Data are collected using a questionnaire organized by core and optional modules.

Mode of Data Collection: Random digit dialing (RDD) landline, RDD cell phones, computer-assisted telephone interviewing (CATI), and web questionnaire (Mokdad, 2009).

Specific Questions Related to CVD, COPD, Asthma, and/or Diabetes: Ever been told you have cardiovascular disease/heart attack and stroke (myocardial infarction/heart attack, coronary heart disease, angina, stroke)?; Daily aspirin intake; stomach problem after aspirin intake; signs and symptoms of a heart attack (weak, lightheaded, faint, chest pain, discomfort, trouble seeing in one or both eyes, pain or discomfort in arms or shoulder, shortness of breath, sudden numbness or weakness of face, arm, leg especially on one side, sudden chest pain, trouble seeing in one or both eyes, severe headache with no known cause); outpatient rehab after stroke; Ever been told you had asthma?; routine check up because of asthma; days unable to work or carry out usual activities because of asthma; symptoms of asthma make it difficult to stay asleep; symptoms of asthma (coughing, wheezing, shortness of breath, chest tightness, and phlegm production without a cold or respiratory infection); child asthma status; Ever been told you have diabetes?; age when were told you have diabetes; insulin/diabetes pills intake; Ever been told you have high blood pressure?; taking medicine for your high blood pressure.

Information Obtained: The BRFSS survey reports information on prevalence of asthma/adult asthma history, cardiovascular disease (heart attack/stroke), diabetes, and health risk factors that include cholesterol and hypertension awareness. BRFSS does not have data on chronic bronchitis or emphysema. Risk factor information about physical activity, fruit and vegetable consumption, smoking, weight, height, BMI, alcohol consumption, diabetes and blood pressure medication, and demographic information (race, gender, age, income, education, children in household, employment status, household income, ethnicity, county of residence, marital status) is collected.

Dissemination of Data: Data files are available online.

California Health Interview Survey

Main Purpose of Study: To provide population-based data on a broad set of health and health-related indicators for California. The data are actively disseminated to reach a broad constituency, including policy makers, researchers, state and county health agencies, community-based agencies and organizations, health advocates, and others to support evidence-based policy and decision making.

Sample: CHIS interviews approximately 50,000 households every two years.

The CHIS sample design includes 41 individual county strata and 3 multicounty strata that include the remaining 17 counties with small populations. Koreans and Vietnamese have been oversampled in every CHIS cycle and other groups in various cycles. The large CHIS sample and racial/ethnic diversity of California permits estimates for all major racial/ethnic groups, plus many sub-ethnic groups as well. CHIS provides distinct samples for Chinese, Filipinos, Japanese, South Asians, Koreans, and Vietnamese, and for Latinos/Hispanics from Mexico, Central America, South America, and European-origin.

CHIS conducts separate interviews for adults (aged 18 and older), adolescents (aged 12 to 17, interviewed

directly), and about children (age 12, with information provided by parental proxy). Both genders are included in the CHIS sample.

Response rate—Please see the CHIS methodology report 4 on response rate at http://www.chis.ucla.edu/methodology.html and also studies of CHIS data quality at http://www.chis.ucla.edu/dataquality.html.

Frequency of Data Collection: Biennial from CHIS 2001 through CHIS 2009; data collection will be continuous beginning with CHIS 2011.

Source of Data: Population interviews with persons living in households

Mode of Data Collection: Random digit dialing landline and cell phones

Specific Questions Related to CVD, COPD, Asthma, and/or Diabetes: Topics vary from CHIS cycle to cycle, but age-appropriate questions related to the chronic conditions listed above have been administered to the adult, adolescent, and child samples.

Information Obtained: Prevalence; functional health outcomes including disability (physical and mental); risk factors, including diet, physical activity, alcohol/drug use, smoking, health screening, interpersonal violence, suicide ideation, falls in elderly, mental health, sexual behaviors, etc.; clinical care information, access to health care, usual source of care, and medical home and care coordination; demographic characteristics, including age, race/ethnicity, geographic region, income, education level, occupation, health insurance status, as well as immigration status, sexual orientation, and other characteristics.

Cost of Survey/Registry: Varies from cycle to cycle.

Who Pays for Data Collection?: Data collection is funded by several sources, including private, state, and federal agencies. Sources of funding vary from cycle to cycle; however, there is a core set of large and consistent supporters of CHIS, including the California Department of Health Care Services, the California Department of Public Health, the California Department of Mental Health, the National Cancer Institute, Kaiser Permanente, The California Endowment, and First 5 California.

Dissemination of Data: Statewide pubic-use files are available online at no charge. For convenience, files are provided in several data formats, including SAS, SPSS, and STATA. Detailed documentation for the data files and their content is also provided. Confidential data files with geographic identifiers and sensitive variables are availability for legitimate research through remote access.

CHIS has an online query system called *Ask*CHIS that is a user-friendly and easily accessible tool for generating data estimates on many health indicators at the state and county levels and at sub-county levels for Los Angeles and San Diego counties. Results can be adjusted and displayed to the user's preferences and output can be displayed as charts, exported to Excel, etc. The data are weighted to the population and rounded to the nearest thousand. The system has more than 20,000 registered users who have made nearly 500,000 queries of the data.

Data access is available to the general public, researchers, county local health departments, federal, state, and community agencies and funders. Those interested in obtaining access to confidential data must apply to use it through a secure data center at the UCLA Center for Health Policy Research. The wide dissemination of the data to achieve usability and application is a priority of CHIS.

Comment: CHIS data are widely used in policy analysis, policy making, seeking funding for health services, research, and news stories and educational efforts. Some of the key impacts of CHIS data are listed in "CHIS Making an Impact" (available at http://www.chis.ucla.edu/chis-impact.html and http://www.chis.ucla.edu/pdf/chis_making_impact.pdf). CHIS data are used in many peer-reviewed research studies, which are listed in http://www.chis.ucla.edu/peerpubs/.

Hawaii Health Survey (HHS)

Main Purpose of Study: The Hawaii Health Survey is a continuous statewide household survey that gathers information on health and socio-demographic conditions.

Sample: In 2004, 6,769 adult respondents in households aged 18 and older; 19,699 household members surveyed. Geographic scope is the state of Hawaii, with indicators that include county, island, ZIP code as reported by the respondent, and telephone prefix.

Frequency of Collection and Sources of Data: The survey is conducted annually.

Mode of Data Collection: Population interviews random telephone dialing; computer-assisted telephone interviewing (CATI).

Specific Questions Related to CVD, COPD, Asthma, and/or Diabetes: Ever been told to have asthma, diabetes, high blood cholesterol, hypertension?; Health data on asthma, diabetes, high blood cholesterol, hypertension, heart, and lung disease.

Information Obtained: Asthma, diabetes, high blood cholesterol, hypertension, health-related quality of life; mental and physical health scores, suicide ideation, smoking, physical activity, intimate partner violence, orphans, housing, hunger, incarceration, age, gender, income, race, education, household size, insurance status, ethnicity by parents, marital status, employment and jobs, poverty status, food insecurity, military, migration.

Dissemination of Data: Summary data tables by condition are available online. The survey does not include households without telephones, Niihau, group quarters, and the homeless. The Office of Health Status Monitoring (OHSM) at the Hawaii Department of Health is responsible for compilation and analysis of data from vital statistics records and a statewide survey.

Healthcare Cost and Utilization Project (HCUP)

Main Purpose of Study: This is an ongoing data project that has spawned over 1,000 research articles. The purpose is to collect hospital, ED, and ambulatory surgery (AS) administrative (claims) data for a wide range of research applications. Full information can be found at www.hcup-us.ahrq.gov. HCUP includes a census of records from participating states, as well as samples of hospital discharges and a national ED sample that provide the ability to make national estimates.

Sample: HCUP currently contains over 90% of all hospital discharges in the United States. The HCUP inpatient data include virtually all discharges from nearly all hospitals in each state that participates—currently 43 states participate in HCUP. Fewer states provide data for ED and AS use. National estimates can be produced for the four census regions; selected state data are also available. Data are available at the local, state, regional, and national levels. Minorities are not oversampled; the data are a census of inpatient discharges, ED visits, and ambulatory surgery encounters from participating states. All age groups and both men and women are included. Response rate—HCUP is not a sample; it contains all records from participating states.

Frequency of Data Collection: Annual, with data since 1988. The number of states has grown over time, so earlier data are based on fewer states. National estimates are possible since 1993.

Source of Data: Administrative (claims) data on hospital discharge records, ED visits, and ambulatory surgery encounters.

Mode of Data Collection: Administrative data collected by state governments, hospital associations, and state data organizations directly from the hospitals. These statewide organizations participate in a voluntary arrangement with AHRQ and provide their data to HCUP for research purposes.

Specific Questions Related to CVD, COPD, Asthma, and/or Diabetes: Contains all records with ICD-9-CM codes for diagnoses and procedures to enable selection of particular populations of interest.

Information Obtained: Data include records of discharges/visit/encounters that can form the numerator of rates using population-based denominators. For most conditions/procedures, this will represent a discharge or visit rates, not prevalence or incidence rates. Functional health outcomes are not collected, and risk factors are not reliably collected using ICD-9-CM codes. The clinical care information that is gathered includes procedures that are coded using ICD-9-CM codes. Demographic characteristics collected include age, gender, patient county, health insurance status, and median household income of patients' ZIP code (available across all data sources); race/ethnicity is available from 38 of 43 states.

Cost of Survey/Registry: This is an ongoing data collection project with data available for over 20 years—not a survey or registry.

Who Pays for Data Collection?: Funded by AHRQ.

Dissemination of Data: Data are not available online but can be obtained through the HCUP Central Distributor: http://www.hcup-us.ahrq.gov/tech_assist/centdist.jsp. Data are available for purchase (states set the prices of the state databases, thus there is a lot of variation across states in the purchase price; the nationwide databases are

available for purchase at prices set by AHRQ). Purchase of all data requires a data use agreement to be signed by the researcher.

The website http://hcupnet.ahrq.gov/ provides access to descriptive statistics from the nationwide data and many states (their participation is voluntary). The online query system is freely available; the data must be purchased. Researchers can purchase the raw data.

Illinois County Behavior Risk Factor Survey (ICBRFS)

Main Purpose of Study: Several states perform broad-based health interview surveys of their states' populations to more accurately identify health risks and to more fully explore ways to address threats to health. These surveys are designed to provide information that meets the needs of policy makers—data that are (a) local, (b) timely, (c) accurate, (d) adequate descriptive, and (e) informative at each intervention level (state, community, family, individual).

In Illinois, the Illinois County Behavior Risk Factor Survey (ICBRFS) has long served this need for adults. But there is no similar health status survey for children and adolescents. Several key institutions in Illinois are working together to build the Illinois Health Survey for Youth (IHSY)—a health survey that would expand what is known about the health of Illinois children and adolescents and support better public health and educational planning.

Sample: The Illinois BRFSS currently collects data from 17,000 adults in Illinois each year, about 5,000 for the statewide strata, and 12,000 for the county-level strata. After three years, each county has a sample of 400 adults. The Illinois Department of Public Health has cooperated in developing a sampling plan that coordinates these two sampling efforts and that would leave open sample for the youth survey. Although there is general agreement on principals, it is not clear that it will be possible to integrate the youth and the Illinois BRFSS survey. When fully operational, a sample of 20,400 surveys of parents on behalf of children and adolescents over a three-year period is expected. Additionally, adolescents would be given a supplemental survey. About 5,000 completed adolescent supplements over a three-year period are expected.

Illinois County BRFSS samples the geographic regions of 95 local health departments (these are typically county level, with a few exceptions). Counties are preferred because that is where local public health policy is made in Illinois. The 51 strata are used to assure that large complex populations have adequate sample and to preserve at least some of the local health department focus of the Illinois BRFSS.

The IHSY will have 51 geographic strata (using PUMAs and SuperPUMAs). In rural regions of the state, PUMAs combine 3–4 counties. In more densely populated areas of the state, SuperPUMAs divide up counties into subsections. For example, Chicago will have 5 geographic strata; Suburban Cook County will have an additional 5.

Minorities are not oversampled. The Illinois County BRFSS samples adults aged 18 and up; IHSY will sample children aged 0–17. Both men and women are included.

The pilot in Chicago yielded an interview completion rate of 28% for the BRFSS and of 55% for the IHSY. Parents were much more willing to talk about the health of their children than to answer questions about themselves.

Frequency of Data Collection: When fully operational, every three years.

Source of Data: Population interviews

Mode of Data Collection: Random digit dial landline; will use a cell phone supplement.

Specific Questions Related to CVD, COPD, Asthma, and/or Diabetes: The Illinois County BRFSS includes the standard BRFSS questions for these. IHST asks about conditions relevant for children and their development. These include asthma and diabetes, health behaviors (PA and nutrition).

Information Obtained: Demographics: Age, gender, race ethnicity, primary language, marital status, household composition, education level, county of residence, ZIP code, number phone lines per household, veteran status, attended school last week. Chronic health conditions: General health, asthma, diabetes, heart attack, angina, coronary artery disease, prostate cancer, birth weight, ADHD (screening, treatment), Autism/Asberger's (treatment), seizures (treatment), hay fever/breathing, skin allergies, food allergies. Acute health conditions: Frequent headaches, stomach pains, growing pains, serious injury, infectious disease (past 12 months), bed time, wake time, snore frequency, nap frequency, days school missed due to health problem.

The survey also collects information on disability, mental health, women's health, disease prevention, injury

prevention, health behaviors, interpersonal violence, healthcare utilization and access, employment, household income and program participation, child care, adult supervision, neighborhood environment.

Cost of Survey/Registry: About $1,000,000 per year for the Illinois County BRFSS. About $800,000 per year for IHSY.

Who Pays for Data Collection?: Illinois County BRFSS is paid for through the Preventive Services Block Grant. IHSY is not yet funded. Negotiations are under way with the Illinois Governor's Office (though it will not be funded this year considering the budget crisis). It has been determined to be eligible for Medicaid matching funds, which will cut the cost to the State of Illinois to $400,000 per year.

Dissemination of Data: Data files are not yet available online (survey not funded). Only the pilot has been conducted. There is a planned online query system which is expected to be public.

Iowa Household Health Survey (IHHS)

Main Purpose of Study: The 2005 IHHS was the second comprehensive, statewide effort to evaluate the health status, access to health care, and social environment of children in families in Iowa. The primary goals of the IHHS were to: (1) assess the health and well-being of children and families in Iowa, (2) assess a set of early childhood issues, (3) evaluate the health insurance coverage of children in Iowa, and (4) assess the health and well-being of racial and ethnic minority children in Iowa.

Sample: The 2005 IHHS was conducted using population-based telephone interviews with a sample of 3,669 families with children in Iowa. It included a targeted oversample of African American and Hispanic children. 331 parents of children from a targeted telephone sample who were identified by a parent as African American (170) or Hispanic (161) were added to the original sample for the purposes of this health disparities study. Two Spanish-speaking interviewers conducted the telephone surveys in Spanish for 105 families who chose to do the interviews in Spanish. The age range was 0–4 yrs., 5–9 yrs., 10–14 yrs., and 15–17 yrs.

Frequency of Data Collection and Sources of Data: Household Health surveys are completed every five years. Interviews were completed with the parents of 3,669 children throughout the state of Iowa.

Mode of Data Collection: Phone numbers dialed included a combination of random digit dial (22%) and phone numbers targeted toward families (78%) and were obtained from a private vendor. Targeted lists came from a variety of resources, including white pages and other lists (e.g., voter registration, magazine subscriptions, and warranty cards).

Specific Questions Related to CVD, COPD, Asthma, and/or Diabetes: In this study, asthma was chosen as a chronic health condition of emphasis. About one of four African American children (23%) have been diagnosed with asthma at some time in their life. In contrast, only 4% of HSI children have been diagnosed with asthma, followed by HEI children (7%), and white children (9%).

1. Have you ever been told by a doctor or other health professional that [CHILD] had asthma?
2. Does [CHILD] still have asthma?
3. How old was [CHILD] when a doctor or other health professional first said [HE/SHE] had asthma?
4. How long has it been since you last talked to a doctor or other health professional about [CHILD]'s asthma? This could have been in a doctor's office, the hospital, an emergency room, or urgent care center. Would you say . . . ?
5. How long has it been since [CHILD] last took asthma medication?
6. Symptoms of asthma include coughing, wheezing, shortness of breath, chest tightness or phlegm production when [CHILD] did not have a cold or respiratory infection.
   a. How long has it been since [CHILD] last had any symptoms of asthma?
   b. Has a doctor or other health professional EVER given you or [CHILD] an asthma action plan?
   c. During the past 12 months, how many different times did [CHILD] stay in any hospital overnight or longer because of [his/her] asthma?

Information Obtained: The % of respondents with asthma diagnosis, child's weight, physical activity, overall eating patterns, parenting stress, child's screen time (TV/computer), medical care and access to health care, pre-

ventive care, age, race/ethnicity of child/parent, education level of child/parent, health insurance status, household income.

Cost of Survey/Registry: Approximately $75,000

Who Pays for Data Collection?: Funding was provided primarily by the IDPH, with additional funding from the U.S. Department of Health and Human Services Maternal and Child Health Bureau (MCHB) and the Centers for Disease Control and Prevention (CDC).

Dissemination of Data: Final report data are presented to the Iowa Legislature, IDPH, and posted to the public website. The final report is available online, but not the data files. The only people with access to the data files are the researchers on the project who have IRB approval.

Los Angeles County Health Survey (LACHS)

Main Purpose of Study: Since 1997, the Los Angeles County Health Survey (LACHS) has functioned as a primary vehicle for gathering information about access to health care, healthcare utilization, health behaviors, health status, and knowledge and perceptions of health-related issues among the LA County population. The overall objective of each survey is to update key health indicators, including health status, health conditions, health-related behaviors, health insurance coverage, and access to care among adults and children living in LA County. Data collected by the survey provide the Department of Public Health and other county and city agencies, along with policy makers, community leaders, academic researchers, and the public itself with information about the health and healthcare needs of LA County residents, in an effort to continuously improve their health status. To address the root causes of poor health, the survey looks beyond individual risk factors for disease to factors in the physical and social environment that influence health, such as availability of fresh fruits and vegetables, availability of community resources for exercise and play, and neighborhood safety.

Sample: The LACHS collects local data from a representative sample of noninstitutionalized LA County residents. Adult Survey: Data collected for the Adult Survey has ranged between 7,200 and 8,648 randomly selected LA County adults (18 years or older). The adult in the household with the most recent birth date is chosen to participate in the survey. The 2007 Adult LACHS surveyed a total of 7,200 individuals, while the 2010 survey will include 8,000 individuals. Adult surveys have also included 7 or 8 subsample sections, each administered to approximately 1,000 adult survey respondents. Child Survey: The Child Survey has collected data from a range of 5,728–6,032 parents or legal guardians of randomly selected children aged 17 years and younger.

Data collection is stratified to provide stable population estimates across the county's 8 service planning areas (SPAs). For most indicators, stable data are also available for the county's 26 health districts, which are subsets of the SPAs. Data are collected regarding respondents' street address or cross streets, city, and ZIP code. Approximately 80% of respondents are geocoded to a Census Tract. Data can also be analyzed by geopolitical regions, including Supervisorial District, Assembly District, State Senatorial District, and Congressional District.

Minorities are not oversampled.

The adult survey includes LA County residents aged 18 and older. Data are routinely analyzed by age groups including: 18–24, 25–29, 30–39, 40–49, 50–59, 60–64, and 65 and over.

The child survey is administered to parents of children and adolescents 0–17 years old, with a majority of questions focusing on children 0–5.

Respondents include males and females, with each group comprising approximately 50% of the sample.

The 2007 LACHS response rate was 18% and 15% for the Adult and Child surveys, respectively, calculated by AAPOR RR3 formula. The response rates achieved in the 2007 LACHS were lower than those achieved in earlier LACHS cycles. (For 2002–2003, RR = 31.1% adult, 33.9% child, and for 2005, RR = 22.8% adult, 26% child.)

The overall cooperation rates for Adult and Child surveys were 40% each (AAPOR COOP3), meaning that 40% of the people successfully contacted by phone were willing to complete the interview with the surveyor.

Frequency of Data Collection: The LACHS has been conducted every 2–3 years since 1997. The 2010 LACHS follows surveys conducted in 1997, 1999, 2002, 2005, and 2007.

Source of Data: Population-based telephone survey of LA County adults (18 years and over) and the parents

or legal guardians of LA County children (17 years or younger). Previous cycles of LACHS included only landline telephones, but 10% of 2010 sample will consist of cell phone users.

Mode of Data Collection: RDD landline and RDD cell phones

Specific Questions Related to CVD, COPD, Asthma, and/or Diabetes: Adult Survey: Questions from the 2007 Adult LACHS pertaining to the above topics included: "Have you ever been told by a doctor or other health professional that you have:" heart disease; diabetes; high blood pressure or hypertension; high blood cholesterol. Furthermore, among those responding in the affirmative to being ever diagnosed with diabetes, follow-up questions included, "How old were you when you were told you have diabetes?" "Are you now taking insulin?" and "Are you now taking diabetes pills?" Past cycles have included a variety of other follow-up questions for adults diagnosed with cardiovascular disease.

Although questions pertaining to asthma did not appear in the 2007 LACHS, they were asked on the 2005 Adult Survey. The Adult Survey also includes many questions related to behavioral risk factors for cardiovascular disease, pulmonary disease, and diabetes, such as items assessing physical activity level, consumption of fruit and vegetables, and smoking status.

Child Survey: Child survey questionnaires assess diagnosis of diabetes and asthma among children. The child survey also includes questions related to cardiovascular disease risk later in life, such as frequency of fast food consumption, frequency of soda or sweetened drink consumption, and physical activity levels.

A copy of the Adult and Child questionnaires and a link to a complete description of the survey's methodology—for the 1999 though 2007 Los Angeles County Health surveys—may be viewed or downloaded from the following LA County Department of Public Health (DPH) Health Assessment Unit's website: http://publichealth.lacounty.gov/ha/hasurveyintro.htm.

Information Obtained: The LACHS collects data on physical activity levels, frequency of fast food consumption, frequency of soda or sweetened drink consumption, fruit and vegetable consumption, access to fresh fruit and vegetables, smoking status, alcohol use, perceived safety of neighborhood, ease of access to parks/playgrounds, mental health status/depression, etc. The LACHS collects data reflecting adults' and children's health and dental insurance status, type of health insurance, availability of regular source of care, difficulty accessing care when needed, and the potential reasons for this difficulty. Data pertaining to care received specifically for cardiovascular disease are not currently collected, but past survey cycles have assessed treatment and clinical services for adults diagnosed with hypertension, diabetes, high cholesterol, etc. Some of the demographic data collected by the LACHS are: age, race/ethnicity, income and education levels, health insurance status, employment status, disability status, place of birth, language spoken at home, and sexual orientation.

Cost of Survey/Registry: The cost of the 2010 LACHS is $1,375,959.

Who Pays for Data Collection?: Funding for the LACHS is derived from programs within LA County's DPH and other programs within the county and/or community. More specifically, funding for the upcoming 2010 survey was received from DPH programs, including Alcohol and Drug Program Administration, Emergency Preparedness and Response Program, Tobacco Control and Prevention Program, and Environmental Health. Other funding was contributed by LA County's Department of Mental Health and First 5 LA.

Dissemination of Data: Although data tables based on the LACHS data are available on the Health Assessment Unit website (http://publichealth.lacounty.gov/ha/hasurveyintro.htm), the actual data sets are available through a research collaboration process, which requires submission of an analysis plan and forms acknowledging adherence to HIPPA regulations and IRB review. The online query system can soon be accessed at the following website: http://publichealth.lacounty.gov/ha/hasurveyintro.htm.

Data tables and publications based on the LACHS data are available to the public at the following Health Assessment Unit website: http://publichealth.lacounty.gov/ha. In addition, customized data requests for community groups, researchers, and other health care providers and advocates are routinely performed. Researchers interested in using the LACHS data set to conduct more in-depth original analyses may obtain the full data set by submitting a research collaboration application.

Comment: Additional limitations of the LACHS data include the following: Data are based on self-report, which can introduce potential inaccuracies in the reported data. Moreover, for all previous survey years (1997–2007), only individuals with landlines were included in the sample, so data exclude those who were currently homeless

or residing in cell-phone-only households. In addition, individuals within "institutionalized" settings (e.g., prison, college dormitories, nursing homes) were not sampled, a factor that can limit the generalizability of the observed data. Finally, given the time constraints of the survey, the content of the questionnaires is necessarily limited.

Medical Expenditure Panel Survey (MEPS), Household Component

Main Purpose of Study: Since 1996, MEPS, a set of large-scale surveys of families and individuals, their medical providers (doctors, hospitals, pharmacies, etc.) and employers across the United States, collect information on utilization, cost, and payment sources of healthcare services and the cost, scope, and breath of health insurance held by and available to U.S. workers. MEPS contains two components: the household component and the Insurance component. The household component gathers data from a sample of families and individuals drawn from prior year's National Health Interview Survey (NHIS). The insurance component gathers data from a sample of private and public employers on the health insurance plans offered to employees. Only the household component contains information on chronic diseases.

Sample: 32,577 individuals of all ages were included in 2006. Data are collected at the national level.

Mode of Data Collection: In-person interviews

Specific Questions Related to CVD, COPD, Asthma, and/or Diabetes: Priority Conditions (Quality Supplement) and Priority Conditions Enumeration include diabetes, asthma, hypertension, coronary heart disease, angina, heart attacks, other heart disorders, strokes, emphysema; Questions include whether adult respondents have ever been diagnosed as having a particular condition and identification of condition code associated with medical events reported during the reference period; Medical conditions and diagnoses not validated.

Information Obtained: Prevalence information is collected. Health status information collected includes limitations in activities of daily living and instrumental activities of daily living, disability days. Demographic information collected includes age, race, ethnicity, income level, insurance status.

Dissemination of Data: Information is online and available to the public.

Minnesota Heart Survey

Main Purpose of Study: The Minnesota Heart Survey began in 1979 as an ongoing surveillance project of cardiovascular disease in the Minneapolis/St. Paul metropolitan area (population 2.6 million, 2000 Census). The origins of the study are found in the NHLBI Conference on the Decline of Cardiovascular Disease and the search for reasons for that decline. The project has been funded in multiple R01s principally from the NHLBI but also from NINDS. It collects mortality, morbidity and population risk factor data at regular intervals in the metropolitan area. The most recent survey was completed in 2009.

Sample: Mortality surveillance is comprehensive, including all deaths in the Minneapolis/St. Paul metropolitan area plus data from citizens dying out of state. Morbidity surveillance includes acute myocardial infarction, stroke, and congestive heart failure. Surveys are at five-year intervals. Surveillance is comprehensive of all metropolitan area hospitals with a 50–100% sample of the target metropolitan population. From 1980–1995 morbidity was collected on hospitalized patients aged 30–74. After that time, the upper age limit was removed and elderly oversampled. Risk factor surveillance is with random population samples are drawn at five-year intervals. Sample size ranges from 4,000–6,000 for each survey. From 1980–1995 the adult population aged 25–74 was surveyed. After 1995, children aged 5–18 were included. At the same time, the upper age restriction was removed. MHS is comprehensive for the Minneapolis/St. Paul metropolitan area. MHS is comprehensive for the Minneapolis/St. Paul metropolitan area. In 1986, an African American cohort aged 30–74 of 1,000 were surveyed. In 2007–2009, Hispanics were oversampled.

Response Rate: Mortality: Death certificate data are comprehensive with over 98% of deaths available. Morbidity data are also comprehensive in MHS based on access to hospital records. There are two exceptions. First, a very small hospital did not allow access for several survey years. That hospital constituted less than 2% of the admissions for the target diagnoses. Second, for one year, a larger hospital required a direct signed consent from hospitalized patients to participate in the congestive heart failure survey. This led to a reduction in participation at

that hospital. Risk Factor Survey: The home interview portion has a response rate of 70–90%. The entire survey, including the clinic visit, has a response rate of 60–70%.

Frequency of Data Collection: Mortality data collection is continuous, with the most recent data complete to 2008. For morbidity data, acute myocardial infarction was collected in 1980, 1985, 1990, 1995, and 2001–2002; stroke data were collected in 1980, 1985, 1990, 1995, and 2000; congestive heart failure data were collected in 1995 and 2000. Risk factor data in the population were collected in 1980–1982, 1985–1987, 1990–1992, 1995–1997, 2000–2002, and 2007–2009.

Sources of Data: Mortality: Minnesota Death Index, National Death Index. Morbidity: abstraction of hospitalization records. Risk factor Survey: Face-to-face interviews and clinic visit.

Mode of Data Collection: Mortality: Computerized death certificates from the state of Minnesota and the National Death Index. Morbidity: Nurse abstraction of hospital records. Risk Factor Survey: Random samples are selected based on a cluster household sampling design and a home interview is followed by clinic visit.

Specific Questions Related to CVD, COPD, Asthma, and/or Diabetes: Mortality: Complete death certificate data are available, including information from next of kin on some sub-studies. Morbidity: Comprehensive data are collected on pre-hospital characteristics, hospital course, and discharge plans. Risk Factor Survey: Extensive data are collected on demographic characteristics, health behaviors, medication use, health knowledge and biological data, including phlebotomy, blood pressure measurement, ankle-brachial index, and other characteristics

Information Obtained: Incidence data are available at a population level. Prevalence data are available at a population level. A sub-study of patients with congestive heart failure and stroke was performed in conjunction with a large HMO in the metropolitan area. The study included multiple indicators of functional health outcomes following hospitalization.

Traditional risk factors are measured, including lipids, hemoglobin 1Ac, smoking with biochemical validation, and others. Questions about stress were asked at certain surveys. Extensive data were gathered on individual subjects from nurse abstraction of hospital records in MHS. All major demographic characteristics were collected, including occupation and health insurance status.

Cost of Survey: 1979–1984 $5.2 million; 1984–1989 $6.3 million; 1989–1994 $9.4 million; 1995–1999 $7.5 million; 1999–2005 $10.2 million; and 2006–2011 $7.1 million. Totals include direct and indirect costs.

Who Pays for Data Collection: Data collection is RO1 supported by NHLBI and NINDS.

Dissemination of Data: Data are available to investigators and data are shared with collaborators around the world. There are multiple sub-studies that have been part of MHS over the years, including hot pursuit of acute myocardial infarction, autopsy study of sudden death, factors associated with women and cardiovascular disease treatment, and many others. These are found in the multiple publications associated with this study.

National Ambulatory Medical Care Survey (NAMCS)

Main Purpose of Study: The National Ambulatory Medical Care Survey (NAMCS) is a general purpose survey of nonfederal office-based physicians and community health centers (CHCs) in the United States. Its purpose is to provide accurate, relevant, nationally representative data annually about visits to these settings. Primary areas of interest include use of healthcare services and resources for different conditions; quality of care, including disparities among diverse populations; and monitoring diffusion of technologies, including drugs, medical procedures, and electronic health record (EHR) systems.

Sample: A substantial proportion of the NAMCS sampling frame is ineligible, for example, because physicians may no longer be in practice or may fall into ineligible categories (see below). In 2010, the expected number of survey responses is 35,000 visits to 1,200 physicians in office-based practice and 280 physician or mid-level providers from about 95 community health centers.

NAMCS uses a multistage probability design that involves probability samples of geographically based primary sampling units (PSUs), physicians within PSUs, and patient visits to physicians. A PSU consists of a county, a small group of contiguous counties, or a metropolitan statistical area (MSA) from the 50 states and the District of Columbia. Prior to sampling 112 PSUs with probability proportional to size, PSUs were stratified into 4 geographic regions (Northeast, South, Midwest, and West), which correspond to those used by the

U.S. Bureau of the Census. Within each of the regions, PSUs were further divided into areas located within or outside MSAs.

The second stage of the NAMCS sampling consists of a probability sample of practicing physicians selected from the master files maintained by the American Medical Association (AMA) and American Osteopathic Association (AOA). Anesthesiologists, radiologists, and pathologists are excluded. Within each PSU, all eligible physicians are stratified into specialty groups. The core NAMCS has 15 strata: general and family practice, osteopathy, internal medicine, pediatrics, general surgery, obstetrics and gynecology, orthopedic surgery, cardiovascular diseases, dermatology, urology, psychiatry, neurology, ophthalmology, otolaryngology, and all other specialties. In some years, external funders have paid for additional specialty groups to be sampled separately. For example, in 2010, CDC's National Center for Chronic Disease Prevention and Health Promotion funded the inclusion of a special stratum of oncologists.

In order to improve the precision of CHC physician estimates, starting in 2006, a dual-sampling procedure has been used to select CHC physicians and other providers. First, the traditional NAMCS sample of physicians is selected using established methods and sources. Second, a sample of 104 CHCs is selected, and within each CHC, up to three physicians, physician assistants, nurse midwives, or nurse practitioners are selected for survey participation. After selection, CHC providers follow the sampling procedure used by NAMCS traditional physicians in selecting patient visits. The list of CHCs is from the Health Resources and Services Administration and the Indian Health Service. To ensure that CHC physicians are included only once, all CHC physicians selected in the traditional NAMCS sample are omitted from the survey response and subsequent weighting.

The final stage is the selection of patient visits within the practices of sampled clinicians. This involved two steps. First, the total physician sample is divided into 52 random subsamples of approximately equal size, and each subsample is randomly assigned to 1 of the 52 weeks in the survey year. Second, a systematic random sample of up to 30 visits is selected during the assigned week. The sampling rate varies for this final step from a 100 percent sample for very small practices to a 10 percent sample for very large practices as determined in a pre-survey interview.

NAMCS is nationally representative and also provides some data by region and location within or outside an MSA. In 2010, the Office of the National Coordinator for Health Information Technology (ONC) funded NCHS to collect data about EHR adoption and use from a supplemental mail survey using a state-based sample of physicians. The state-based EMR supplement has a different modality and includes less content than the core survey, but it illustrates the flexibility of adding more geographic detail.

As noted above, data are gathered about visits to physicians in office-based practice. Therefore, the data are representative of physician visits, not the general U.S. population. Moreover, information is available only for people who are treated in a physician's office or community health center. People who do not seek medical care in one of these settings have no opportunity to have their data included in the survey. All age groups, sexes, and racial and ethnic groups are included. Minorities are not oversampled, but because PSUs are sampled with probability proportional to size, adequate representation is anticipated of populations that are concentrated in large metropolitan areas.

Response rate: In 2007, the most recent year for which final response rate information is available, the final unweighted response rate and the response rate weighted to account for the probability of selection were both 61 percent.

Frequency of Data Collection: Annual

Source of Data and Mode of Data Collection: For the core survey, data about clinicians and their practices are gathered using a paper and pencil questionnaire during an in-person interview. Data from a sample of visits are obtained by abstracting information from the medical record for the sampled visit. Initially, NAMCS was designed for clinicians to complete the forms in real time from visits as they occurred. In reality, when clinicians complete these forms, they do so by abstracting data from their own records. To improve response rates, each sampled clinician is given the option of having forms completed by a member of his or her office staff or by a trained NAMCS field representative. In 2007, more than half of the abstractions were performed by NAMCS field representatives, with clinicians completing fewer than 10 percent of the forms. Mail surveys are used for the state-based supplemental survey on EMRs.

Demographic Composition of National Ambulatory Medical Care Survey, 2007

	Unweighted Frequency	Unweighted Percent
Age Group		
Less than 15 years old	5,161	14.9
15–24 years old	2,852	8.2
25–44 years old	7,160	20.6
45–64 years old	10,408	30.0
65–74 years old	4,498	13.0
75 years or older	4,598	13.3
Missing	15	0.0
Sex		
Female	19,994	57.6
Male	14,423	41.6
Missing	275	0.8
Race and Ethnicity		
Non-Hispanic White	15,074	43.5
Non-Hispanic Black	2,655	7.7
Hispanic	2,421	7.0
Asian	733	2.1
Native Hawaiian/Other Pacific Islander	60	0.2
American Indian/Alaskan Native	273	0.8
Multiple races	69	0.2
Missing race or ethnicity	13,407	38.6

Specific Questions Related to CVD, COPD, Asthma, and/or Diabetes: For each sampled visit, the patient record form includes a series of check-boxes to indicate whether the patient currently has asthma, cerebrovascular disease, congestive heart failure, COPD, diabetes, hyperlipidemia, hypertension, or ischemic heart disease. The 2010 patient record form is available at http://www.cdc.gov/nchs/data/ahcd/NAMCS_30A_2010.pdf.

Information Obtained: The incidence of health events that trigger a visit to physician offices or CHCs may be estimated for specific diagnoses (as determined by ICD-9-CM coding). The data collection form distinguishes visits for flare-ups of chronic conditions, such as asthma attacks, from routine visits for chronic conditions.

The visit data that NAMCS collects cannot determine the prevalence of a particular chronic condition in the population, since a patient may well visit multiple providers. The prevalence of a specific chronic condition among a clinician's patients may be estimated. The form collects data on selected chronic conditions that the patient has, regardless of the reason or diagnosis for the sampled visit. That information could be coupled with the number of visits a patient has had to that provider during the past 12 months to estimate the number of patients with a specific condition that that provider has.

The survey does not collect information on functional health outcomes. Information is available on some risk factors when this information is recorded in the medical record. For example, body mass index is available only when the patient's height and weight were recorded for the sampled visit. A series of check-boxes indicate whether the patient currently has asthma, chronic renal failure, diabetes, hyperlipidemia, hypertension, ischemic heart disease, or obesity. Other risk factors for which information is gathered include current tobacco use and blood pressure at the time of visit. Up to 8 medications ordered, administered, or continued may be recorded. The results of laboratory results being collected from 2010—namely total cholesterol, high-density lipoprotein, low-density lipoprotein, triglycerides, glycohemoglobin, and fasting plasma glucose for tests performed in the 12 months prior to the sampled visit by the sampled provider—will provide additional information on risk factors.

The survey is designed to focus on clinical care. One can, for example, estimate total use of physician office care for patients with COPD or diabetes. Similarly, one can examine the content of services delivered to patients by diagnosis or blood pressure levels, including the specific medications that are being prescribed.

Patient record forms include the following:

- verbatim reason for visit and up to three visit diagnoses;
- regardless of visit diagnosis, a series of check-boxes indicate whether the patient has asthma, cerebrovascular disease, chronic renal failure, congestive heart failure, COPD, diabetes, hyperlipidemia, hypertension, ischemic heart disease, or obesity;
- major reason for visit (new problem, chronic problem, routine; chronic problem flare-up, pre-/post-surgery; preventive care);
- the names of up to 8 medications ordered, supplied, administered, or continued during the visit (which are coded using the Multum system);
- other services ordered or provided, including health education, and blood and imaging tests; and
- continuity of care, including whether the physician is the patient's primary care provider, whether the patient is new or has been seen before, and how often the patient has been seen in the past year.

In 2010, NAMCS is gathering data on the results of laboratory tests of total cholesterol, high-density lipoprotein, low-density lipoprotein, triglycerides, glycohemoglobin, and fasting plasma glucose, if the clinician ordered these tests in the 12 months prior to the sampled visit. The plan is to continue to collect these data in future years.

Data are collected on patient's date of birth, sex, ethnicity, and race. The specific ethnicity categories collected are Hispanic or Latino and Not Hispanic or Latino. The specific race categories collected are as follows: White, Black/African-American, Asian, Native Hawaiian/Other Pacific Islander, American Indian/Alaskan Native, and more than one race. Data are also collected on the expected source(s) of payment for the visit. Patient ZIP code data are gathered and linked to Census socio-demographic variables for the patient's Zip Code Tabulation Area.

Cost of Survey/Registry: $6.1 million for FY 10, excluding the central NCHS infrastructure.

Who Pays for Data Collection?: NCHS pays for collection of core data elements. Sponsors pay for developmental work, additional data elements, and supplemental modules associated with their topics of interest. For example, ONC is sponsoring the state-based EMR mail supplement.

Dissemination of Data: All public-use files are available online, free to anyone. The files have undergone disclosure review to minimize potential for disclosure of organizations and individuals included in the survey. These files are usually released within 15 months of the end of data collection period, which is about 19 months after the end of the calendar year. There is no online query system. The data are available at http://www.cdc.gov/nchs/ahcd/ahcd_questionnaires.htm.

Comments:

- NAMCS also collects data about the clinician and his or her practice. For example, information is collected on ownership; practice size; patient volume; physician specialty; medical technologies on-site; and availability, use, and features of EHR systems. These data make it possible to examine associations among characteristics of the clinician, the practice organization, patient, and clinical management of the patient's care.
- The NAMCS PSU sample has not been updated since 1988 because of resource constraints.
- High rates of missing data on race and ethnicity (above 30%) were noted in the 2006–2008 samples. These increases were concurrent with the rapid rise of the proportion of data collection forms completed by NAMCS field representatives. In 2009, efforts were made to reduce the amount of missing data through better training of field representatives and more reminders about the importance of these data to researchers. NCHS will continue to reinforce field representatives' training about the methods and importance of these data. There is optimism that efforts under way will help address the missing problem, but there is not yet a final data set for use in assessing the full impact. To the extent that missing data remain a problem for these key variables, NCHS is also developing procedures to conduct multiple imputation for these critically important data fields.
- NAMCS is still a paper and pencil activity. Conversion to computerized data collection and more general conversion to collect data from electronic data sources must be addressed as the healthcare information technology infrastructure changes. Preliminary estimates from 2009 NAMCS data indicate that only 6% of office-based physicians, especially those in large practices, have fully functional EHR systems. Therefore, it is not yet possible to reply on electronic systems for nationally representative data. As recent legislation may change this landscape dramatically, NAMCS is planning for that eventuality.

- Other important/promising future activities include increasing sample sizes to produce state estimates and collection of longitudinal data. These activities would require additional resources. To better assess patients' risk factors and the appropriateness of care, NAMCS could expand the data collected on clinical management and risk factors during the 12 months before the sampled visits. For patients with hypertension, hypercholesterolemia, or prior stroke, for example, the survey could collect the number of visits, medications, prescribed, changes in medications, and family history.

National Diabetes Surveillance System (NDSS)

Main Purpose of Study: The National Diabetes Surveillance System is a comprehensive assembly of diabetes-related data from national and state-based surveys, including household surveys such as the National Health and Nutrition Examination Surveys (NHANES), telephone surveys such as the Behavioral Risk Factor Surveillance System (BRFSS), and other data sources. There are several important attributes or characteristics of the NDSS:

- It is the only diabetes surveillance system at the national level that collects, analyzes, and disseminates national, state, and county data on the growing public health burden of diabetes and its complications.
- It is dynamic, responding to changes in scientific knowledge and public health priorities.
- Unlike many surveillance systems, which typically rely on one or two data collection systems, the NDSS is a complex system that uses a variety of survey and data systems to describe and monitor the public health burden of diabetes and its complications.
- It adapts national and state health survey systems to allow the development and monitoring of key indicators, including national health objectives. Examples include the addition of the diabetes and prediabetes modules to the BRFSS. Also, in collaboration with the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), the diabetes and pre-diabetes component of NHANES was developed.
- It serves as a model for the diabetes surveillance activities of states and Division of Diabetes Translation provides diabetes surveillance technical assistance internal to CDC and to other federal agencies (e.g., CMA, VA, IHS) and the international community.
- Unlike many surveillance systems, which only describe the burden of disease in the U.S. population, the NDSS also describes the burden of the disease in a specific population—the population with diabetes. For example, it describes health care utilization for complications in the diabetic population, preventive care practices received by this population, and risk factor reduction in this special population.
- It uses a variety of mechanisms (fact sheets, publications, Internet) to disseminate diabetes surveillance data to a variety of audiences (e.g., policy makers, professional organizations, state health department). One example is the National Diabetes Fact Sheet (available at http://apps.nccd.cdc.gov/DDTSTRS/FactSheet.aspx).
- Information from the NDSS enables CDC to lead a consensus process among a dozen or more public and private agencies to derive national estimates and information on the burden of diabetes and its complications in the United States.

Because diabetes is a complex disease that affects nearly every organ system of the body, the scope of the NDSS is broad. Although the NDSS first began assessing diabetes prevalence, mortality, and long-term complications, it progresses to assessing preventive care practices, risk factors, and risk behaviors and is beginning to move more upstream to the surveillance of at-risk populations.

Sample: 3,141 counties or county-equivalence, 50 U.S. states, and the District of Columbia. Historically, the NDSS contained only national- and state-level estimates, but recently county-level estimates of diabetes and obesity prevalence derived from Bayesian multilevel modeling techniques have been included (http://apps.nccd.cdc.gov/DDT_STRS2/NationalDiabetesPrevalenceEstimates.aspx). Generally, disaggregation of trends by demographic characteristics is more likely to be feasible at the national level than at the state level because of sample size issues, and the NDSS contains no data for geographic units smaller than counties. Minnesota, Montana, New Mexico, North Carolina, and Oklahoma have conducted surveys with an oversample of American Indians. The survey includes all ages.

Frequency of Collection and Sources of Data: Annual. County-level diagnosed diabetes prevalence derived from the Behavioral Risk Factor Surveillance System (BRFSS) and the U.S. Census Bureau's Population Estimates Program.

Mode of Data Collection: Vital statistics, ongoing national, state, and local data collection systems, billing data collected by Medicare, Medicaid, managed care organizations, survey data from NCHS (e.g., BRFSS), hospital inpatient data, the U.S. Renal Data System (USRDS); preventive care practices data include physical exam results from hemoglobin A1c testing, lipid tests, foot and eye exams, self-monitoring of blood sugar, tests of kidney function (Desai, 2003).

Specific Questions Related to CVD, COPD, Asthma, and/or Diabetes: Dilated eye exam, daily self-monitoring of blood glucose, foot exam, doctor visit for diabetes, daily self-exam of feet, A1c tests, ever attended diabetes self-management class

Information Obtained: Incidence and prevalence data are collected. Functional health outcome information includes poor physical health, poor mental health, inability to do usual activities, limitations in mobility. Risk factor information is collected about physical inactivity, overweight, obesity, current smoking, hypertension, high blood cholesterol. Clinical care information is collected about mortality; diabetes-related use of healthcare services, disability, and preventive care practices, and mortality and health service use related to complications of diabetes. Where feasible, trends are examined by demographic characteristics (age, race/ethnicity, education, sex, and geographic level).

Who Pays for Data Collection?: BRFSS, state health departments

Dissemination of Data: Data are available online.

National Health and Nutrition Examination Survey (NHANES)

Main Purpose of Study: The National Health and Nutrition Examination Survey is the largest and longest-running national source of objectively measured health and nutrition data on children and adults across the United States.

Sample: NHANES surveys about 5,000 people from counties across the United States annually. The survey includes civilian noninstitutionalized men and women of all ages in the United States. NHANES oversamples those who are 60 and older, African Americans, and Hispanics

Frequency of Collection and Sources of Data: NHANES is conducted annually and includes a series of questionnaires that are used in both the home and the mobile center, a physical examination, and a laboratory component.

Mode of Data Collection: There are six instruments used for data collection. These are:

1. Screener module administered on the doorstep;
2. Family questionnaire that collects household and family level information, including demographics and occupation;
3. Sample Person questionnaire that includes questionnaire hand cards and target topics that include blood pressure, cardiovascular disease, demographics, diabetes, and respiratory health and disease;
4. Audio computer assisted personal interview (ACASI) and computer assisted personal interview (CAPI) questionnaires that are administered in the mobile examination center (MEC);
5. Special follow-up questionnaires that include the flexible consumer behavior survey and Hepatitis C follow-up; and
6. Examination and laboratory components that include the dietary recall, body measurements, and the environmental health profile.

Specific Questions Related to CVD, COPD, Asthma, and/or Diabetes: The NHANES questionnaire collects information on chronic conditions, including blood pressure and cholesterol, cardiovascular disease, diabetes, and respiratory health and disease.

Information Obtained: Prevalence, risk factors, and functional health outcomes

National Health Interview Survey (NHIS)

Main Purpose of Study: National Health Interview Study data are used widely throughout the Department of Health and Human Services (HHS) to monitor trends in illness and disability and to track progress toward achieving national health objectives. The data are also used by the public health research community for epidemiologic and policy analysis of such timely issues as characterizing those with various health problems, determining barriers to accessing and using appropriate health care, and evaluating federal health programs.

Sample: The theoretical targeted sample size is 35,000 households and 87,500 persons; however, in recent years, budget limitations have restricted the sample size. In 2008, for example, about 29,000 households and 74,000 persons were in the NHIS sample, including about 9,000 sample children and 22,000 sample adults. All states and the District of Columbia are included in the sample; geographic stratification is a factor in the sampling design. Although all states are included in the NHIS, the sampling design is primarily aimed at making national and regional estimates. Larger states (currently approximately 20) have sufficient coverage in their samples so that reliable estimates can be made. Black, Hispanic, and Asian populations are oversampled for the family questionnaire. Persons over 65 years of age and in one of these three minority groups also have a greater probability of being selected as the sample adult. Persons of all ages are included in the NHIS sample. Persons of both sexes are included in the NHIS sample. The response rate varies by section of the questionnaire; the response rate for the first section (the family questionnaire) was 84.5% in 2008, the sample child final response rate was 72.3%, and the sample adult final response rate was 62.6%.

Frequency of Collection and Sources of Data: Data are collected annually and continuously, with a different cross-sectional sample each year. NHIS is conducted primarily by personal interviews in households with interviewers from the U.S. Census Bureau. Following the family questionnaire, which covers everyone in the family, one sample adult and (if any are in the family) one sample child are randomly selected. The sample adult answers for him/herself and a "knowledgeable" adult answers for the sample child.

Mode of Data Collection: NHIS is an in-person survey. After the initial in-person interview, completion of sections such as the sample adult questionnaire can sometimes be done by telephone.

Specific Questions Related to CVD, COPD, Asthma, and/or Diabetes: A standard set of questions are asked each year of the sample adult and respondent for the sample child to obtain data on these conditions; in some years, additional questions may be asked about these conditions in the supplemental questionnaires, which vary by year. Additionally, persons who experience limitation in a wide variety of activities are asked which conditions cause the limitation; some of the categories are related to these diseases.

Information Obtained: Incidence estimates can be roughly calculated for adult diabetes; not for other mentioned conditions. For conditions causing limitation, incidence can also be roughly calculated. Prevalence information can be calculated for the conditions listed under specific questions that include hypertension/high blood pressure, coronary heart disease, angina or angina pectoris, heart attack, stroke, asthma, chronic bronchitis, diabetes, emphysema.

Limitations caused by most of these conditions is available; however, if a person has multiple limitations caused by multiple conditions, specific limitations cannot be attributed to specific conditions. Some related stressor data are collected in the NHIS including height/weight, body mass index, smoking and drinking behaviors, serious psychological distress, poverty, and unemployment. Depending on what is considered a "stressor," there may be other data available.

The care data collected in the NHIS are relatively general and, in almost all cases, not tied to specific conditions. There are standard questions about the quantity of various kind of care obtained from various sources. Not infrequently, NHIS supplemental questionnaires collect more detailed data on care that is more likely to pertain to specific conditions. A wide variety of demographic characteristics are collected in the course of the NHIS, including all of those mentioned above. The survey also collects information on personal earnings (as opposed to family income), country of birth, and citizenship status for all family members, employment status for all family members aged 18 or older, and industry and occupation data for a randomly selected adult in the family (e.g., the sample adult). In addition, information on health insurance coverage and race/ethnicity for each family member is quite detailed (although not all of this information is available on the public-use data files).

Cost of Survey: The NHIS costs about $30 million per year. NCHS covers the cost of the core survey; supplement sponsors cover the cost of the supplements. Sponsoring agencies are almost always other federal government agencies and, most commonly, NIH.

Dissemination of Data: Public-use files are released annually (and, fairly recently, back through 1963). Except for some variables that might pose a disclosure risk, all variables are on these files, with some collapsing of categories. All public-use files are available to anyone with Internet access. Additional access to variables with some disclosure risk or variables that can be linked to other sources of data (e.g., geocoding) can be obtained through a Research Data Center with approval of a proposal; there is a charge for this service.

National Hospital Ambulatory Medical Care Survey (NHAMCS)

Main Purpose of Study: The National Hospital Ambulatory Medical Care Survey is a general purpose survey of nonfederal noninstitutional hospitals with outpatient departments (NHAMCS-OPD) and emergency departments (NHAMCS-ED) in the 50 states and the District of Columbia. In addition, NHAMCS includes freestanding and hospital-based ambulatory surgery centers (NHAMCS-ASC). NHAMCS's purpose is to provide accurate, relevant, nationally representative data annually about visits to these settings. Primary areas of interest include use of healthcare services and resources for different conditions; quality of care, including disparities among diverse populations; monitoring diffusion of technologies, including drugs and medical and surgical procedures and EHRs; and ED crowding.

Sample: In 2010, expected numbers of survey responses are 100,000 patient visits to 360 hospitals with OPDs, EDs, or ASCs, and 200 freestanding ASCs. Sample design and geographic stratification: NHAMCS uses a multistage probability design that involves probability samples of geographically based primary sampling units (PSUs); samples of hospitals within PSUS; samples of OPDs, EDs, and ASCs within hospitals; and samples of visits within each setting. A PSU consists of a county, a small group of contiguous counties, or a metropolitan statistical area (MSA) from the 50 states and the District of Columbia. Prior to sampling 112 PSUs with probability proportional to size, PSUs were stratified into 4 geographic regions (Northeast, South, Midwest, and West) that correspond to those used by the U.S. Bureau of the Census. Within each of the regions, PSUs were further divided into areas located within or outside MSAs.

Within PSUs, hospitals were stratified by hospital class, type of ownership (not-for-profit, nonfederal government, and for-profit) and hospital size. The original sample for the NHAMCS frame was compiled as follows. Hospitals with an average length of stay for all patients of fewer than 30 days (short-stay) or hospitals whose specialty was general (medical or surgical) or children's general were eligible for NHAMCS. Excluded were federal hospitals, hospital units of institutions, and hospitals with fewer than six beds staffed for patient use.

The original NHAMCS sample was drawn from the universe of 6,249 hospitals in the 1991 SMG Hospital Database that met the survey's eligibility criteria. Of the eligible hospitals, 5,582 (89%) had emergency departments (EDs) and 5,654 (90%) had outpatient departments (OPDs). Hospitals were defined to have an ED if the hospital file indicated the presence of such a unit or if the file indicated a non-zero number of visits to such a unit. A similar rule was used to define the presence of an OPD. Hospitals were classified into four groups: those with only an ED, those with an ED and an OPD, those with only an OPD, and those with neither an ED nor an OPD. Hospitals in the last class were considered as a separate stratum, and a small sample (50 hospitals) was selected from this stratum to allow for estimation to the total universe of eligible hospitals and the opening and closing of EDs and OPDs in the sampled hospitals.

A fixed panel of 600 hospitals was selected for the NHAMCS sample; 550 hospitals had an ED and/or an OPD and 50 hospitals had neither an ED nor an OPD. To recognize the possibility of seasonality in healthcare delivery, the sample of 600 hospitals was randomly divided into 16 subsets of approximately equal size. Each subset was assigned to 1 of the 16 4-week reporting periods, which rotate across survey years. Therefore, the entire sample does not participate in a given year, and each hospital is inducted approximately once every 15 months. Over time, hospitals close and new ones open. Therefore, the NHAMCS sample is refreshed every 3 years. The sample was refreshed most recently in 2009 using the SDI Market Profiling Database to construct the sampling universe.

Within each hospital, either all outpatient clinics and emergency service areas (subsets of EDs) or a sample

of such units is selected. Outpatient clinics are in scope if ambulatory medical care is provided under the supervision of a physician and under the auspices of the hospital. Clinics are required to be "organized" in the sense that services are offered at established locations and schedules. Clinics where only ancillary services were provided or other settings in which physician services were not typically provided are out of scope. An ED is in scope if it is staffed 24 hours a day.

For freestanding ASCs, a list sample was constructed by combining information from a commercial Freestanding Outpatient Surgery Center Database and Medicare-certified facilities included in the CMS Provider-of-Services (POS) file. Facilities specializing in dentistry, podiatry, abortion, family planning, or birthing were excluded. Prior to sampling, ASCs were stratified by facility specialty and geographic region.

Within each sampled setting, patient visits are systematically selected over a randomly assigned 4-week reporting period. A visit is defined as a direct personal exchange between a patient and a physician or a staff member acting under a physician's direction for the purpose of seeking care and rendering health services. Visits solely for administrative purposes, such as payment of a bill, and visits in which no medical care was provided, such as visits to deliver a specimen, are out of scope.

Geographic levels included in sample (e.g., local, state, national): NHAMCS is nationally representative. The sample is stratified into 4 geographic regions (Northeast, South, Midwest, and West) that correspond to those used by the U.S. Bureau of the Census. Within each of the regions, PSUs are further stratified by whether or not they are located within or outside MSAs. With additional resources, NHAMCS has the capacity for state-based sampling and estimation.

Demographic composition of the sample: As noted above, data are gathered about visits to hospital ambulatory units, including OPDs, EDs, and ASCs, as well as freestanding ASCs. The data are representative of healthcare visits to these settings and do not represent the general U.S. population. Moreover, information is available only for people who are treated in these settings; people who do not seek medical care in one of these settings have no opportunity to be included in the survey. All age groups and both males and females are included in the sample. Minorities are not oversampled, but because PSUs are sampled with probability proportional to size, adequate representation is anticipated of populations that are concentrated in large metropolitan areas.

Response rates: In 2007, the most recent year for which final response rate information is available, the unweighted response rates were 84% for NHAMCS-ED and 72% for NHAMCS-OPD. Response rates weighted to account for the probability of selection were 86% and 61% for NHAMCS-ED and NHAMCS-OPD, respectively. Response rates for NHAMCS-ASC are not yet available because hospital-based ASCs were added in 2009 and freestanding ASCs were added in 2010.

Frequency of Data Collection: Annual

Source of Data and Mode of Data Collection: Data about ambulatory care facilities are gathered using a paper and pencil questionnaire during an in-person interview. Data from a sample of visits are obtained by abstracting information from the medical record for the sampled visit.

NHAMCS was designed with the intention that hospital staff within the sampled department would complete the patient record form. To improve response rates, each sampled unit is also given the option of having forms completed by a trained NHAMCS field representative. In 2007, more than half of the abstractions were performed by hospital staff. Field representatives completed about one-third of the abstractions. The remainder was completed by a combination of hospital and survey staff (7%), or the person who completed the form was not noted (2%).

Specific Questions Related to CVD, COPD, Asthma, and/or Diabetes: Content varies by setting.

- NHAMCS-OPD. For each sampled visit, the patient record form includes a series of check-boxes to indicate whether the patient currently has asthma, cerebrovascular disease, congestive heart failure, COPD, diabetes, hyperlipidemia, hypertension, or ischemic heart disease.
- NHAMCS-ED. For each sampled visit, the patient record form includes a series of check-boxes to indicate whether the patient has cerebrovascular disease or history of stroke, congestive heart failure, or diabetes. Vital signs at the time of triage are recorded. These include blood pressure, heart rate, respiratory rate, pulse oximetry, and whether the patient was on oxygen.
- NHAMCS-ASC. No specific questions relate to these conditions, though the form collects diagnoses and procedures.

Demographic Composition of National Hospital Ambulatory Medical Care Survey, 2007*

	Unweighted Frequency	Unweighted Percent
Age Group		
Less than 15 years old	12,500	17.9
15–24 years old	10,175	14.5
25–44 years old	19,506	27.9
45–64 years old	17,506	25.0
65–74 years old	4,791	6.8
75 years or older	5,411	7.7
Missing	74	0.1
Sex		
Female	40,396	57.7
Male	29,126	41.6
Missing	441	0.6
Race and Ethnicity		
Non-Hispanic White	30,302	43.3
Non-Hispanic Black	12,610	18.0
Hispanic	6,550	9.4
Asian	1,590	2.3
Native Hawaiiann/Other Pacific Islander	290	0.4
American Indian/Alaskan Native	239	0.3
Multiple races	772	1.1
Missing	17,610	25.2

*The 2007 sample contained ED and OPD data only.

See patient record forms: http://www.cdc.gov/nchs/data/ahcd/nhamcs100ed_2010.pdf, http://www.cdc.gov/nchs/data/ahcd/nhamcs100opd_2010.pdf, http://www.cdc.gov/nchs/data/ahcd/nhamcs100asc_2010.pdf.

Information Obtained: The survey does not collect information on functional health outcomes. The incidence of events that trigger a visit to an OPD, ED, or ASC may be estimated for specific diagnoses (as determined by ICD-9-CM coding). The ED data may be one of the best nationally representative sources for the incidence of acute events or conditions, such as AMI, for which the patient is expected to come to the hospital. Admissions to the hospital, by principal discharge diagnosis, are also recorded. ED data would, of course, exclude people who died and were not brought to a hospital. In concert with NHLBI and CDC's National Center for Chronic Disease Prevention and Health Promotion, methods are being developed, for example, using troponin results that are intended to more accurately identify AMIs than has been possible with ICD-9-CM codes alone. Though developed for inpatient discharges, the methods may be applicable to improve estimates of incidence using ED data as well.

The data collection form distinguishes visits for flare-ups of chronic conditions such as asthma attacks from routine visits for chronic conditions. The visit data that NHAMCS collects cannot determine the prevalence of a particular chronic condition in the population, however, since a patient may well visit multiple providers. For OPDs, the prevalence of a specific chronic condition among a clinic's patients may be estimated. The form collects data on selected chronic conditions that the patient has, regardless of the reason or diagnosis for the sampled visit. That information could be coupled with the number of visits a patient has had to that provider during the past 12 months to estimate the number of patients with a specific condition that that provider has.

Demographic data: Data are collected on the patient's date of birth, sex, ethnicity, and race. Data are also collected on the expected source(s) of payment for the visit. Patient ZIP code data are gathered and linked to Census socio-demographic variables for the patient's ZIP Code Tabulation Area.

Risk factors/stressors: For NHAMCS-OPD, information is available on some risk factors when this information is recorded in the medical record. For example, body mass index is available when the patient's height and weight were recorded for the sampled visit. A series of check-boxes are available to indicate whether the patient currently has certain conditions, including asthma, cerebrovascular disease, COPD, diabetes, hyperlipidemia,

hypertension, ischemic heart disease, or obesity. Other risk factors for which information is gathered include current tobacco use and blood pressure at the time of visit. Up to eight medications ordered, administered, or continued may be recorded. From 2011, the plan is to gather laboratory results for total cholesterol, high-density lipoprotein, low-density lipoprotein, triglycerides, glycohemoglobin, and fasting plasma glucose for tests performed in the 12 months prior to the sampled visit by the sampled provider.

For NHAMCS-ED, for each sampled ED visit, a series of check-boxes are available to indicate whether the patient has cerebrovascular disease or a history of stroke, congestive heart failure, diabetes, or a condition requiring dialysis; pulse oximetry; and whether the patient is on oxygen. Up to eight medications administered or prescribed may be recorded. Vital signs include initial blood pressure.

For NHAMCS-ASC, other than diagnoses and procedures, the abstraction does not collect data on risk factors.

Clinical care: For NHAMCS-OPD, information is obtained on clinical care information including verbatim reason for visit; up to three visit diagnoses (ICD-9-CM coded); regardless of visit diagnosis, a series of check-boxes indicate whether the patient has asthma, cerebrovascular disease, chronic renal failure, congestive heart failure, COPD, diabetes, hyperlipidemia, hypertension, ischemic heart disease, or obesity major; reason for visit (new problem, chronic problem, routine; chronic problem flare-up, pre-/post-surgery; preventive care); the names of up to eight medications ordered, supplied, administered, or continued during the visit; other services ordered or provided, including health education and blood and imaging tests; and information about continuity of care, including whether the clinician is the patient's primary care provider, whether the patient is new or has been seen before, and how often the patient has been seen in the past year. One can, for example, examine all primary care visits for patients with high blood pressure and analyze the medications and other services prescribed for these patients by characteristics of the patient and the hospital.

For NHAMCS-ED, data elements collected include the patient's initial vital signs at triage assessment (temperature, blood pressure, heart rate, respiratory rate, pulse oximetry, patient on oxygen, coma scale, pain scale); verbatim reason for visit; up to three visit diagnoses (ICD-9-CM coded); a series of check-boxes indicate whether the patient has cerebrovascular disease or history of stroke, congestive heart failure, diabetes, or conditions requiring dialysis; the names of up to 8 medications ordered or administered; other services and procedures performed (including BUN/creatinine, cardiac enzymes, glucose, cardiac monitor, ECG/EKG); information on previous care in the same ED in the past 72 hours and 12 months, and discharge from a hospital within past 7 days; information about patient flow, including length of time to initial treatment by a physician and total visit length; and visit disposition, including admission to the hospital, the type of unit to which admission occurred, and final discharge diagnosis. Visit times may be especially interesting, as there is some suggestion that hospital inpatients admitted following prolonged stays in the ED may have worse outcomes.

For NHAMCS-ASC, data elements collected include up to 5 visit diagnoses (ICD-9-CM coded); up to 7 surgical procedures; time in the operating room before, during, and after surgery; up to 12 prescriptions and over-the-counter medications and anesthetics administered during the visit or provided or prescribed at discharge; and details about anesthesia administration, including the type(s) of anesthesia and the training and specialty of the provider. Information about surgical outcomes, including symptoms present during and after the procedure, discharge to the ED or hospital, and medical care sought at 24 hours is also gathered.

Cost of Survey/Registry: $5.9 million, not including the central NCHS infrastructure

Who Pays for Data Collection?: NCHS pays for collection of core data elements. Sponsors pay for developmental work, additional questions, and supplemental modules associated with their topics of interest. For example, in 2010 NCI and CDC are collaborating to develop a colonoscopy supplement to the NHAMCS-ASC module.

Dissemination of Data: Public-use files are available online, free to anyone. The files undergo disclosure review to minimize the potential for disclosure of hospitals and individuals included in the survey. These files are usually released within 15 months of the end of data collection period, which is about 19 months after the end of the calendar year. A prototype for an online query system to include NHAMCS-ED data is currently under development. It is hoped that other data sets will be included in the future. The data are available at http://www.cdc.gov/nchs/ahcd/ahcd_questionnaires.htm.

Comments: The biggest challenges are lack of timeliness, lack of longitudinal data to provide better information on transitions and outcomes, and inadequate sample sizes to produce state estimates. All of these barriers

could be overcome with increased resources. To better assess patients' risk factors and the appropriateness of care, like the potential described above for NAMCS, NHAMCS-OPD could expand the data collected on clinical management and risk factors during the 12 months before the sampled visits. For patients with hypertension, hypercholesterolemia, or prior stroke, for example, the survey could collect the number of visits, medications, prescribed, changes in medications, and family history.

NHAMCS is still a paper and pencil activity. Conversion to computerized data collection and more general conversion to collect data from electronic data sources must be addressed as the healthcare information technology infrastructure changes. Although there are still too few hospitals with electronic systems to gather the representative data through health information exchange, recent legislation is expected to change this landscape dramatically. Options are being explored for gathering data electronically through a single integrated National Hospital Care Survey to cover OPD, ED, ASC, and inpatient care. In addition to ultimately providing data in a more timely fashion, the integrated survey would permit patient linkage for care across these hospital settings in the future permit linkage with the National Death Index and CMS databases.

National Hospital Discharge Survey (NHDS)

Main Purpose of Study: The National Hospital Discharge Survey is a continuing general purpose survey of inpatient hospital care in the United States, ongoing since 1965. Its purpose is to provide accurate, relevant, nationally representative data annually about hospital discharges. Primary areas of interest include monitoring trends in the use of hospital care for different conditions, describing demographic characteristics of patients receiving hospital care for different conditions, and monitoring diffusion of new medical and surgical procedures to treat specific conditions.

Sample: About 150,000 inpatient discharges from 239 hospitals annually for 2008 through 2010. In 2007 and prior years, sample sizes were approximately twice as large. Sample design and geographic stratification: The scope of NHDS encompasses discharges from noninstitutional hospitals, excluding federal hospitals, located in the 50 states and the District of Columbia. Only hospitals having six or more beds staffed for inpatient use are included in the survey. General (medical and surgical) and children's general hospitals are included, regardless of length of stay, but other hospitals are included only if they have an average length of stay fewer than 30 days. The 1988 sample was selected from a frame of short-stay hospitals listed in the 1987 SMG Hospital Market Data Base. The NHDS redesign in 1988 implemented a modified 3-stage design that employed stratification by creating both primary sampling unit (PSU) and hospital strata defined within the four major Census regions and based on characteristics such as metropolitan statistical areas (MSAs)/non-MSA status and data collection type (manual or automated). Units selected at the first stage of sampling consisted of either hospitals or geographic areas (i.e., PSUs), such as counties, groups of counties, or MSAs. Within the sampled PSUs, additional hospitals were selected with probabilities proportional to their annual number of discharges. Finally, at the last stage, discharges within hospitals were selected using systematic random sampling. Third-stage sampling rates were determined by the hospital's sampling stratum and the data collection method used. The target sample for manual system hospitals was 250 discharges annually, whereas discharges from some automated hospitals were oversampled, depending on whether NCHS received a sample or a census file of their discharges. The hospital sample has been updated approximately every 3 years to allow for hospitals that opened or changed their eligibility status since the previous sample update. Hospitals that were no longer eligible for NHDS have been deleted.

Geographic levels included in sample: NHDS is designed to make national, as well as regional estimates, where regions are defined to be the four major Census regions: Northeast, Midwest, South and West. With additional resources, NCHS has the capacity for state-based sampling and estimation of information about inpatient hospital care.

Demographic composition of the sample: As noted above, data are representative of inpatient hospital discharges, where "inpatient" is defined by the hospital. Because the survey samples discharges, not patients, a small number of sampled records may be readmissions; however, the survey does not have a mechanism to track these cases. Patients of all ages, sexes, races, and ethnicities are included in the sample.

Response rate: In 2007, the most recent year for which final response rate information is available, the unweighted response rate was 88%. The response rate weighted to account for the probability of selection was 82%.

Frequency of Data Collection: Annual. Data are gathered throughout the year. 2010 is the last year that NCHS plans to conduct the current NHDS (see Comments below).

Source of Data and Mode of Data Collection: Two data collection procedures are used for the survey. The first is a manual system of sample selection and data abstraction, which was used for approximately 55% of the responding hospitals in 2007. The second is an automated method, which was used for approximately 45% of the responding hospitals in 2007. The automated method involves the purchase of computerized data files from abstracting services or state data systems, or transmissions from the hospitals themselves.

In the manual system, the sample selection and the transcription of information from the hospital records to abstraction forms are performed at the hospitals. Of the hospitals using this system in 2007, about 23% had the work performed by their own medical records staff. In the remaining hospitals using the manual system, personnel of the U.S. Bureau of the Census did the work on behalf of NCHS. The completed forms, along with sample selection control sheets, were forwarded to a contractor for coding and data entry, and then to NCHS for editing and weighting.

For the automated system, NCHS purchased files containing machine-readable medical record data from which records were systematically sampled by NCHS. All the information comes from Uniform Billing (UB)-04 forms, the format in which hospitals submit claims for payment.

Specific Questions Related to CVD, COPD, Asthma, and/or Diabetes: See medical record abstraction form at http://www.cdc.gov/nchs/data/hdasd/nhds_form_updated.pdf.

Information Obtained: Frequencies and rates of inpatient hospitalizations for specific diagnoses (determined by ICD-9-CM coding) are useful in describing disease burden. To the extent that acute events, such as acute myocardial infarction, result in hospital admissions, and are properly diagnosed, national hospital discharge data may represent the best opportunity for monitoring incidence nationally. Improvements to these data are possible, and as noted below under Comments, NCHS has been working with NHLBI and CDC to better realize that potential.

The survey does not collect information on the prevalence of conditions or functional health outcomes.

Demographic data: Data are collected on the patient's date of birth, sex, ethnicity, and race. Data on ethnicity are missing at such a high rate that the missing rate, and the data themselves, are not reported and are not used routinely. For example, for 2007, 49% of the discharge records in NHDS data set had ethnicity missing. Data are also collected on the expected source(s) of payment for the visit.

Risk factors/stressors: Limited to those coded as diagnoses or procedures. For example, some discharge diagnoses, such as diabetes, may be risk factors for others, such as heart disease or stroke.

Clinical care: Information is obtained on up to 7 discharge diagnoses and 4 procedures performed. Data are also collected on admission and discharge dates and discharge status. Beginning in the 2001 survey year, two additional items were included in the medical abstract form: type of admission and source of admission. In late 2007, an admitting diagnosis and a present on admission check-box for all of the diagnosis variables were added to data collection because hospitals were required to collect this information for billing effective at that time.

Cost of Survey/Registry: $2.5 million for FY 10, excluding the central NCHS infrastructure

Who Pays for Data Collection?: NCHS pays for data collection.

Dissemination of Data: Public-use files are available online, free to anyone. The files undergo disclosure review to minimize the potential for disclosure of hospitals and individuals. Currently, development is a prototype for an online query system that will include NHAMCS-ED data, and NHDS hopes to include other data sets in the future. The data are available at http://www.cdc.gov/nchs/nhds/nhds_questionnaires.htm.

Comments: Historically, to minimize the burden on hospitals and to ensure complete and representative data, NHDS has been tied to the UB-04. Unfortunately, this has limited the flexibility of the survey to gather more detailed information. Over the past 5 years, NHDS has tested methods to selectively sample discharged patients with specific characteristics (especially diagnoses) and obtain additional information from the medical records of these discharged patients. Part of this process has involved testing an acute coronary syndrome (ACS) module in collaboration with NHLBI and CDC's National Center for Chronic Disease Prevention and Health Promotion. The purpose of this module is to gather laboratory data to improve the validity of AMI discharges identified solely on the basis of discharge diagnosis. The ACS module tested the collection of troponin data from discharges with a diagnosis of acute myocardial infarction (AMI) or other acute and subacute ischemic heart disease (ICD-9-CM:

Demographic Composition of National Hospital Discharge Survey, 2007

	Unweighted Frequency	Unweighted Percent
Age Group		
Less than 15 years	62,392	17.1
15–44 years old	100,047	27.4
45–64 years old	83,881	22.9
65 years or older	119,328	32.6
Sex		
Female	215,106	58.8
Male	150,542	41.2
Race		
White	191,058	52.3
Black/African American	51,303	14.0
American Indian/Alaskan	1,134	0.3
Native Asian	3,863	1.1
Native Hawaiian/Other Pacific Islander	198	0.1
Other	9,488	2.6
Multiple race	152	0.0
Missing	108,452	29.7

410-411). These tests illustrated that it was possible both to systematically oversample specific discharge diagnoses and to obtain information on troponins from patients with a discharge diagnosis of AMI or other acute and subacute ischemic heart disease. Further developmental work is needed to evaluate the usefulness of this module in monitoring the incidence of AMI, from hospital discharges with and without a discharge diagnosis of AMI. Important next steps include (1) testing the ACS module in a larger sample of discharges from a more varied set of hospitals and (2) testing the feasibility of gathering similar data from patients with other discharge diagnoses, such as old myocardial infarction; angina pectoris; other forms of chronic ischemic heart disease; hypertensive heart disease; cardiac dysrhythmia; heart failure; and acute edema of the lung, unspecified.

A new hospital survey with the flexibility to include such modules as well as linkages with the National Death Index and CMS databases is planned for the future. That integrated National Hospital Care Survey would permit linking patients' care across OPD, ED, ASC, and inpatient hospital settings. The integrated survey would rely on electronic transmission of UB-04 data and clinical data from EHR systems, as the capabilities in the new national sample of hospitals permit.

New York City Community Health Survey

Main Purpose of Study: The Community Health Survey (CHS) is conducted in order to inform public health policy and practice in New York City, making data use and dissemination cornerstones of the project. The CHS data have three main roles in public health work: instrumental, that is, influencing health program decisions; conceptual, that is, increasing the understanding of the relationship between health behavior and health status; and ersuasive, that is, supporting health policies

Sample: Approximately 9,500 interviews each year since 2002. It includes men and women aged 18 and older. The CHS uses a stratified random sample to produce neighborhood and citywide estimates. Strata are defined using the United Hospital Fund's (UHF's) neighborhood designation, modified slightly for the addition of ZIP codes added since the initial UHF definitions. There are 42 UHF neighborhoods in NYC, each defined by one or more adjoining ZIP codes. Response rates vary by year. For the most recent survey for which data are publicly available (2008 CHS), AAPOR Response Rate #3=33.3%, Cooperation Rate #3=80.7%

Frequency of Collection and Sources of Data: Annually since 2002; Population interviews

Mode of Data Collection: Telephone interviews using RDD landline sample (2002–2008) and RDD landline and cellular telephone sample (from 2009 on)

Specific Questions Related to CVD, COPD, Asthma, and/or Diabetes: The CHS contains multiple measures related to these conditions. Multiple health surveillance measures, varies by year. Questionnaires for each year can be downloaded at http://www.nyc.gov/html/doh/html/survey/chsdata.shtml.

Information Obtained: Multiple health surveillance measures. Not all measures are asked each year. Most are designed to provide prevalence estimates. Risk factor information is limited self-report (e.g., asked if taking medications for hypertension). Multiple demographic variables are collected, including age, ethnicity, race, ZIP code location, household income, education level, employment status, health insurance status, and others.

Who Pays for Data Collection: The cost of running the survey is approximately $1 million per year. It is funded with a city tax levy. External (grant and private) funds have supported some modules of the CHS in the past.

Dissemination of Data: SAS-formatted data sets 2006–2008 are available at http://www.nyc.gov/html/doh/html/survey/chsdata.shtml. Data sets for 2002–2005 are available directly from the DOHMH. Along with data from the 2009 CHS, these will be posted to the public website in the future. Visit EpiQuery at http://www.nyc.gov/html/doh/html/epi/epiquery.shtml. Data sets are publicly available.

New York City Community Health Survey Heart Follow-up Study

Main Purpose of Study: The primary objective of the CHS Heart Follow-up Study is to estimate a baseline population sodium intake for NYC; Secondary objectives are to: estimate mean sodium intake by race/ethnicity; estimate the prevalence of awareness, treatment, and control of hypertension; assess the relationship between blood pressure (both self-reported and physical measurement) and sodium intake; and assess the relationship between potassium intake and blood pressure.

Sample: Approximately 1,800 interviews from the CHS 2010 will be completed, resulting in about 1,500 usable urine samples. The surveys will be conducted citywide. Men and women aged 18 and older are included.

Frequency of Collection and Sources of Data: April through August 2010. A follow-up study is planned for 2014, if funding is available. Sources of data are population interviews with some clinical measures.

Mode of Data Collection: Telephone interviews using RDD landline and cellular telephone sample, plus 24-hour urine collection and in-person clinician measurements of height, weight, waist circumference, and resting blood pressure

Specific Questions Related to CVD, COPD, Asthma, and/or Diabetes: In addition to the CHS 2010 questions, participants in the Heart Follow-up Study complete a brief questionnaire including questions on nutrition and personal and family history of CVD.

Information Obtained: Measures will include items from the 2010 CHS as well as a separate series of questions related to dietary sodium consumption. Multiple variables, including age, ethnicity, race, ZIP code location, household income, education level, employment status, health insurance status, and other will be collected.

Who Pays for Data Collection?: The OPTS cost of the 2010 CHS Heart Follow-up Survey is approximately $1.2 million. The Robert Wood Johnson Foundation provided about $566K, Kellogg Foundation provided $98K, New York State Health Foundation provided $181K, and the Centers for Disease Control and Prevention provided $88K in support of the study. NYC DOHMH has funded about $22K through city tax levy funds.

Dissemination of Data: When the study has been completed, data will be accessible via EpiQuery and used for a range of agency and city activities. The data set will be publicly available.

New York City Health and Nutrition Examination Survey

Main Purpose of Study: Specific objectives of NYC HANES are to: estimate the number and percent of persons in the NYC population with selected diseases and risk factors; estimate citywide awareness, treatment, and control of selected diseases; estimate prevalence, awareness, treatment, and control of selected diseases among a limited set of demographic subgroups identified by race/ethnicity, gender, and broad age bands; monitor prevalence and

magnitude of environmental exposures in NYC; analyze risk factors for selected diseases in NYC; and establish a population-based serologic repository that can be used to explore emerging public health issues in NYC.

Sample: Noninstitutionalized adult New York City residents aged 20 years or older. 3-stage cluster sampling design (geographic segment, household, individual). Of the 4,026 households randomly selected for the survey, eligibility screening questionnaires were completed for 3,388 households and 3,047 study participants were identified. Of those identified, 1,999 individuals participated in the survey, yielding a response rate of 55%. Post stratification weighting based on age group, sex, race/ethnicity, borough was applied to minimize the impact of component and item nonresponse.

Frequency of Collection and Sources of Data: The survey was conducted once in 2004. It will repeat as serial cross-sectional at regular intervals, if funding is available. Sources of data are population interviews with clinical measures.

Mode of Data Collection: face to face computer-assisted interviews; audio computer-assisted self-interview (drug use, sexual behavior, incarceration, violence); and physical exam with blood draw, urine collection, and anthropometry (10% conducted in home; 90% in clinic).

Specific Questions Related to CVD, COPD, Asthma, and/or Diabetes: Yes. The questionnaires can be downloaded at http://www.nyc.gov/html/doh/html/hanes/datasets.shtml.

Information Obtained: Prevalence and incidence of selected diseases and risk factors for selected diseases; awareness, treatment, and control of selected diseases; and the prevalence and magnitude of environmental exposures. Demographic information collected includes multiple variables, including age, ethnicity, race, household income, education level, employment status, health insurance status, and others.

Cost of Survey: For HANES, personnel is a costly due to fieldwork. In 2003–2005, total cost was $3,397,273. Lowball estimate for a second NYC HANES with same design is $5 million. This includes a contract for survey operations, but no contract for technical support for sampling, training, or IT.

Who Pays for Data Collection?: 2004 NYC HANES funded by NYC DOHMH almost exclusively through city tax levy funds. Most field staff were reassigned from their regular jobs at DOHMH, and school nurses were paid overtime. No funds have been identified for a second NYC HANES. DOHMH contracted with NCHS to provide IT and other technical support. NYC DOHMH is seeking external funding in collaboration with academic partners.

Dissemination of Data: Variable lists, documentation, codebooks, and data sets are available at http://www.nyc.gov/html/doh/html/hanes/datasets.shtml. Visit EpiQuery: https://a816-healthpsi.nyc.gov/epiquery/EpiQuery/NYCHANES/index.html. Data sets are publicly available.

New York City Youth Risk Behavior Survey

Main Purpose of Study: The YRBS data have three main uses: instrumental, that is, the data influence health education program decisions; conceptual in that they increase the understanding of the health status of New York adolescents; and persuasive in that they support health policy positions. The Bureau of Epidemiology Services uses YRBS data in Vital Signs publications on health behaviors of NYC public high school students.

Sample: 1,500–10,000 annually. From 1993 through 2001, the NYC YRBS was designed to provide data on a citywide level. In 2003 the survey was expanded to provide borough-level data. It was further expanded in 2005, 2007, and 2009 to data for the three District Public Health Office (DPHO) areas in the South Bronx, North and Central Brooklyn, and East and Central Harlem, as well as borough and citywide estimates. It includes public high school students (grades 9–12) in New York City. The YRBS does not include students in juvenile detention centers. English as a Second Language (ESL) and special education classes in otherwise-eligible high schools are also excluded from the sample. The overall response rate for each YRBS stratum needs to be at least 60% to be used.

Frequency of Collection and Sources of Data: Data are collected every other year since 1993 through population interviews.

Mode of Data Collection: Self-administered, paper questionnaire

Specific Questions Related to CVD, COPD, Asthma, and/or Diabetes: The YRBS is designed to monitor priority health-risk behaviors that contribute to the leading causes of mortality, morbidity, and social problems among youth in New York City. The questionnaire measures tobacco, alcohol and drug use; behaviors that contribute to

unintentional injury and violence; sexual behaviors; dietary behaviors; and physical activity. It also monitors the prevalence of obesity and asthma.

Information Obtained: Prevalence and incidence of selected diseases and risk factors for selected diseases; awareness, treatment, and control of selected diseases; and the prevalence and magnitude of environmental exposures. Multiple demographic variables are collected, including age, ethnicity, and race.

Who Pays for Data Collection?: The OPTS cost of the 2009 YRBS was $180,000. It is funded with CDC dollars and city tax levy.

Dissemination of Data: Variable lists, documentation, codebooks, and data sets are available at http://www.nyc.gov/html/doh/html/episrv/episrv-faq-yrbs.shtml. Data sets are publicly available. Visit EpiQuery: https://a816-healthpsi.nyc.gov/epiquery/EpiQuery/NYCHANES/index.html.

Primary Care Information Project

Main Purpose of Study: Tracking of medical care indicators for improving the delivery of recommended preventive services (list limited to cardiovascular related indicators): Aspirin/antithrombotic therapy, blood pressure control, cholesterol control, smoking cessation intervention, diabetes care indicators (A1c test, A1c control, lipid screening, lipid control), asthma symptom assessment and control (ages 5–56, adult and pediatric indicators can be stratified).

Sample: Nearly 1,800 providers are using the EHR system, representing over 100,000 encounters per month. The data base will increase in the next two years as an estimated additional 2,500 providers will be transmitting information to PCIP. The geographic stratification is citywide. The geographic levels included are provider, practice, ZIP code, borough, and citywide. The age ranges are currently based on quality metric collected (e.g., blood pressure control measure age range includes patients 18 to 75).

Frequency of Collection and Sources of Data: All providers with EHR have the capacity to transmit the data. Estimated 80% of practices with EHRs are transmitting information. Data are collected monthly.

Mode of Data Collection: Automated medical chart abstraction facilitated by electronic health records maintained by independent primary care practices (this currently includes small practices, community health centers, and outpatient hospitals) Automated electronic transmission of extracted data fields from the medical charts to a secure data warehouse maintained by PCIP.

Specific Questions Related to CVD, COPD, Asthma, and/or Diabetes: Smoking status, smoking cessation intervention, A1c control (< 7%), A1c testing, antithrombotic tx (IVD or DM), body mass index, BP Control in DM (130/80), BP Control in HTN (140/90), BP Control in IVD (140/90), cholesterol control (genl pop), cholesterol screen (genl pop), LDL control (high risk), LDL testing (high risk), asthma symptom assessment, asthma control (18–56 yrs), depression screening, depression follow-up, depression control, alcohol use screening

Information Obtained: CVD disease and risk factor prevalence among all patients seen by providers transmitting data to PCIP; control among those with select CVD risk factors as per accompanying quality indicators. Limited patient characteristics as information is aggregated to the provider or practice. Provider and practice demographics currently collected include ZIP code, % Medicaid patients, % Uninsured patients, encounters, number of providers, and FTE of providers.

Who Pays for Data Collection: Costs incurred include staffing, associated hardware and software purchases, and maintenance. Estimated $1.2 million per year. It is funded by a New York City tax levy; HEAL5 and HEAL 10 grants from New York State; Regional Extension Center funding from the Office of the National Coordinator for Health Information Technology; Communities Putting Prevention to Work—Tobacco Cessation—Centers for Disease Control; Centers of Excellence—Centers for Disease Control; Agency for Healthcare Research and Quality; Robin Hood Foundation

Dissemination of Data: The data are currently used for internal program operations (technical assistance, coaching on quality improvement). Summarized trends and population averages will be made available in the future. Currently, only PCIP staff and providers can access their own data. In the future, summarized information will be made publicly available.

State Cardiovascular Health Examination Survey

Main Purpose of Study: CDC Division for Heart Disease and Stroke Prevention fund Arkansas, Kansas, Oklahoma, and Washington to collect data on measured levels of blood pressure and blood cholesterol; compare data between priority and general populations; provide information to guide development, implementation, evaluation of cardiovascular health promotion and risk factor control strateiges; reduce the burden of heart disease and stroke-related death, disabilities, and cost; eliminate health disparities. Based on the findings, states will develop hypertension and cholesterol control strategies.

Frequency of Collection and Sources of Data: Started in 2005. The source of data is questionnaire.

Mode of Data Collection: Interview and health exam

Specific Questions Related to CVD, COPD, Asthma, and/or Diabetes: Arkansas: blood pressure knowledge/history, cholesterol knowledge/history, cardiovascular disease knowledge/history, diabetes knowledge/history; Kansas: blood cholesterol, LDL/HDL, triglycerides, blood sugar, HbA1C, Medical history (MI, Angina/CHD, Stroke, TIA, Atrial fibrillation, deep venous thrombosis, pulmonary embolus, peripheral arterial disease, left ventricular heart hypertrophy, other heart disease, hospitalization on selected heart conditions, symptoms of angina, congestive heart failure, peripheral arterial disease, heart attack and stroke symptoms, personal history of blood pressure, cholesterol, diabetes, family history of blood pressure, heart attack, high cholesterol, diabetes, apnea); Oklahoma: actions to control high blood cholesterol, history of cholesterol checked, actions to control high cholesterol, history of CHD/angina, stroke, other cardiovascular diseases, diabetes, aspirin use, rehab following heart attack, stroke, family health history; Washington: HDL, LDL, VLDL, triglycerides, glucose, blood pressure, pulse

Information Obtained: Smoking and tobacco use, drinking, weight history, diet behavior and nutrition, supplement use, physical activity, stress aspirin use. Arkansas: age, gender, ethnicity/race, education, income, marital status, employment/occupation, household composition (number of adults, number of children), housing

Cost and Who Pays for Data Collection?: Arkansas: $1.1 million in cash, $250,000–$300,000 in kind; Kansas: $800,000 in cash, $250,000 in kind. Funded by the Centers for Disease Control and Prevention's Division for Heart Disease and Stroke Prevention.

Dissemination of Data: Data are not publicly available.

Youth Risk Behavior Surveillance System

Main Purpose of Study: To monitor priority health risk behaviors among youth.

Sample: Varies by component; National Survey ~15,000; In 2007, the national YRBSS received 14,103 questionnaires across 157 schools; state, territorial, tribal, and local surveys ~2,000 per site. National, state, territorial, local, tribal levels have separate surveys. The national survey oversamples black and Hispanic students; measure of size was modified so that it would be more likely to select schools with disproportionately high minority enrollment; two classes per grade were selected in schools with large number of minority students.

High school students in grades 9–12; There is a middle school questionnaire available as well, but it is done by only 10 to 15 sites per cycle and not at the national level. Response rate varies by survey. In 2007, the school response rate was 81%, the student response rate was 84%, and the overall response rate was 68%.

Frequency of Collection and Sources of Data: Every other year, usually during the spring semester of odd numbered years. Students complete the self-administered paper and pencil questionnaire during one class period and record their responses directly on a computer-scannable booklet or answer sheet.

Specific Questions Related to CVD, COPD, Asthma, and/or Diabetes: Ever been told by a doctor or nurse that they had asthma?; Ever told by a doctor or nurse that they had asthma and still have asthma?

Information Obtained: Asthma, obesity, health risk behaviors. Behaviors that contribute to unintentional injuries and violence; tobacco use; alcohol and other drug use; sexual behaviors that contribute to unintended pregnancy and sexually transmitted diseases (STDs), including the human immunodeficiency virus (HIV) infection; unhealthy dietary behaviors; and physical inactivity. Grade level/education level, sex, race/ethnicity.

Cost of Survey and Who Pays for Data Collection?: For the entire surveillance system, the cost is about $6 million per cycle. CDC has funding available across 50 state education agencies and a small number of territories, tribal governments, and large urban school districts during each five-year funding cycle.

Dissemination of Data: The national YRBSS are available in ASCII, SPSS, SAS data, SAS formats, and Access formats; go to www.cdc.gov/yrbs; click on National Data Files and Documentation. The public may contact YRBSS for state and district-specific data access. The latest report of 2007 national, state, and local results: http://www.cdc.gov/mmwr/PDF/ss/ss5704.pdf.

The 2009 YRBSS results were released in June 2010.

QUALITY PERFORMANCE MEASURES

Healthcare Effectiveness Data and Information (HEDIS)—Health Plan

Main Purpose of Study: To evaluate performance of health plans; HEDIS Health Plan includes HMOs and PPOs

Sample: Mandatory or voluntary (Medicare Advantage) reporting of 702 HMO products and 277 PPO products. A product is an insurance plan at a state level, segmented by Medicare, Medicaid, and Commercial. The total number of covered lives in the plans reporting HEDIS data is estimated at 116 million. Information is collected by state, reported by region. Geographic levels are national, state, regional, and individual plan. Age groups are dependent on the measure; 0–18 for child-related measures, 18–85 for adults, with older ages variable with measure. Response rate: About 85% of HMOs and 40% of PPOs report data—missing plans are mostly smaller Medicaid and commercial plans.

Frequency of Collection and Sources of Data: Annual data collection reported by plans in May of the year following services

Claims data (diagnoses, procedures, laboratory and pharmacy claims) augmented in some cases by clinical chart reviews (with specified sample size) and patient surveys (random sample of a specific sample size).

Mode of Data Collection: Health Plan Consumer Assessment of Healthcare Providers and Systems (CAHPS), a public–private initiative to develop standardized surveys of patients' experience with ambulatory and facility-level care (HEDIS Measures 2010, NCQA website).

Specific Questions Related to CVD, COPD, Asthma, and/or Diabetes: Clinical measures for cardiovascular disease, chronic pulmonary disease, asthma, and diabetes; 2010 HEDIS summary measures include appropriate testing for children with pharyngitis, appropriate treatment for children with upper respiratory infection, avoidance of antibiotic treatment in adults with acute bronchitis, use of spirometry testing in the assessment and diagnosis of COPD, pharmacotherapy of COPD exacerbation, persistence of beta-blocker treatment after a heart attack, comprehensive diabetes care, relative resource use for people with diabetes, relative resource use for people with asthma, relative resource use for people with cardiovascular conditions, relative resource use for people with uncomplicated hypertension, and relative resource use for people with COPD (HEDIS Measures 2010, NCQA website).

Information Obtained: Incidence—indirectly; prevalence—indirectly; functional health outcomes—only with HOS survey used for Medicare advantage plans; risk factors, including stressors—depending on measure but not stressors; clinical care information—with measures; demographic characteristics: Patient level data ONLY in HOS survey (Medicare Advantage plans)

Who Pays for the Data Collection?: Plans pay for data collection at MD and patient level; they then submit data in aggregate to NCQA via a standard data collection tool.

Dissemination of Data: Processed data available via the NCQA Quality Compass. Anyone can purchase a license to use data within set of restrictions dealing with commercial use of data. Special arrangements can be made for research use. Health plans submit data in aggregate to NCQA via a standard data collection tool.

Healthcare Effectiveness Data and Information (HEDIS)—Physicians

Main Purpose of Study: To evaluate physician office practices

Sample: Open to qualified medical practices (mostly primary care). Practice level data; reported by practice within state and national. All ages are included. About 15,000 physicians in 1,000 practices are recognized.

Frequency of Collection and Sources of Data: Every 3 years. Medical record review.

Mode of Data Collection: Standardized web-based data collection tools; Provision for direct reporting from some EMR installations

Specific Questions Related to CVD, COPD, Asthma, and/or Diabetes: All clinical data, no surveys from patients. 2010 HEDIS measures for physicians include appropriate treatment for children with upper respiratory infection; controlling high blood pressure; cholesterol management for patients with cardiovascular conditions; comprehensive ischemic vascular disease; comprehensive diabetes care; use of appropriate medications for people with asthma; use of spirometry testing in the assessment and diagnosis of COPD; and pharmacotherapy management of COPD exacerbation (HEDIS Measures 2010, NCQA website). Practice-level demographics; language diversity of membership; race/ethnicity diversity of membership (NCQA website).

Dissemination of Data: Researchers can apply to use the data.

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Appendix B

International Studies of Cardiovascular Disease and Chronic Obstructive Lung Disease

HEART DISEASE

AMIS Plus Registry (Switzerland). This nationwide prospective registry included patients hospitalized with an acute coronary syndrome (ACS) between 1997 and 2006 in academic and nonacademic hospitals throughout Switzerland (n ~20,000 patients).

ARIAM (Analysis of Delay in AMI) Project. This registry included all patients hospitalized with an ACS at 119 Spanish hospitals between 1995 and 2001. A total of 17,761 patients were admitted to participating ICU's/CCU's with acute myocardial infarction (AMI).

Canadian Cardiovascular Outcomes Research Team—Quebec. The study sample consisted of patients admitted with a first AMI from the 18 administrative regions of Quebec between 1988 and 1995. This study was performed to examine regional variation in the management of patients hospitalized with AMI throughout Quebec; more than 76,000 patients were included in the computerized database.

CARMELA (Cardiovascular Risk Factor Multiple Evaluation in Latin America). Cross-sectional study that was carried out in adults between the ages of 25–64 years who resided in major cities in 7 Latin American countries. This study was designed to examine the prevalence of several cardiovascular disease (CVD) risk factors and common carotid artery intima-media thickness.

Copenhagen City Heart Study. This study, which has been performed in the Danish general population since the early 1980s, was a prospective study of more than 10,000 individuals between the ages of 30–70 years who were randomly selected from the city of Copenhagen and were subsequently followed over time for the development of fatal and nonfatal CVD events.

EUROASPIRE (European Action on Secondary Prevention Through Intervention to Reduce Events) Surveys. The first EUROASPIRE Survey was conducted in 1995/1996 and was carried out in hospitals in 9 European countries in patients < 80 years of age with coronary heart disease (CHD). Subsequent surveys were carried out in 1999/2000 and 2006/2007. In the last survey, patients with CHD from 76 centers in 22 countries throughout Europe were included.

EuroHeartSurvey ACS. Study was performed in clusters of academic and nonacademic hospitals treating patients with an ACS (AMI or unstable angina) in 25 countries throughout Europe and the Mediterranean basin (total n ~10,000) during 2000/2001.

European Physical Activity Surveillance System (EUPASS). Designed to monitor physical activity and its determinants in random population samples of adults ≥ 18 years from 8 European Union member states (Belgium, Finland, France, Germany, Italy, Netherlands, Spain, United Kingdom). This project was funded by the Health Monitoring Programme of the European Commission.

French USIC (Unité de Soins Intensits Coronaires) Project. This was a nationwide registry of patients hospitalized with AMI during a 1-month period in 1995 and 2000. Patients between the ages of 30–89 years comprised the study sample. The total sample size was 4,347, and participating ICUs represented more than 80% of those treating patients with AMI in France.

Heart of Soweto Study. This investigation studied persons presenting to a large tertiary care clinic in Soweto, South Africa, over a 1-year period (2006) with either incident or prevalent CVD (n = 4,162). This registry included predominantly black Africans who presented to the Chris Hani Baragwanath Hospital, which provides cardiac care to residents of Soweto and surrounding communities.

Hellenic Multicenter Study of Acute Myocardial Infarction. This registry included consecutive patients hospitalized with an AMI (n = 7,433) during a 1-year period (1993/1994) at 76 (out of a total of 86) hospitals throughout Greece.

International Network of Field Sites With Continuous Demographic Evaluation of Populations and Their Health (INDEPTH). This international network includes 34 health and demographic surveillance systems in 17 low and middle-income countries designed to identify the magnitude of non-communicable diseases in these countries. Of these, 23 sites are in Africa, 10 sites are in Asia, and 1 is in Oceania. Risk factor surveys are being carried out in selected study sites to compile baseline data for purposes of subsequent intervention trials.

Italian National Register of Major Coronary Events: Attack Rates in Different Areas of the Country. National register initiated in Italy at the end of the 1990s designed to develop surveillance of fatal and nonfatal coronary events in the general Italian population aged 35–74 years using MONICA criteria.

Italian Network for Obesity and Cardiovascular Disease Surveillance: A Pilot Project. Pilot project implemented in 2006 to evaluate the feasibility of a surveillance network for CVD and obesity in Italian men and women aged 35–74 years. The study lasted 2 years and involved 40 general practitioners from the Italian Association of General Practitioners throughout Italy.

Maximal Individual Therapy in Acute Myocardial Infarction (MITRA Registry). This study enrolled all persons with new onset diabetes from 1972 on at the Laxa Primary Health Care Center in Orebro County, Sweden. A total of 776 incident cases of diabetes reported to this health care center through 2001 were included in this register.

MONICA (Monitoring Trends and Determinants in Cardiovascular Disease). This was a large multinational study that was designed to monitor trends in fatal and nonfatal CHD and strokes, and trends in CVD risk factors, in men and women aged 25–64 years from 38 populations in 21 countries between the mid-1980s and mid-1990s.

Myocardial Ischaemia National Audit Project (MINAP). This study included all acute care hospitals in England and Wales (n = 229) treating patients with an ACS. Data were prospectively collected at participating hospitals between 2003 and 2005. More than 100,000 patients were included in this large multisite observational study.

National Hospital Discharge Register (Sweden). This national registry was established in 1996 and linked hospital discharge data with a national mortality registry of all fatal and nonfatal cases of AMI occurring in Sweden between 1987 and 1995. A total of ~354,000 cases of AMI in adults 30–89 years occurred over this period.

PREVENCION Study (Peru). This study was designed to determine the prevalence of CVD and its risk factors in the adult population of Arequipa, Peru, the second largest city in Peru. It is one of the first population-based studies of CVD in Latin America.

Purwarejo (Indonesia) Demographic Surveillance Site. Using the WHO STEPwise protocol for surveillance, this study examined risk factors for CVD in nearly 3,000 women aged 15–74 years at the Purwarejo (Indonesia) Demographic Surveillance Site in 2001.

REACH Registry (REduction of Atherothrombosis for Continued Health). This is a prospective registry designed to provide up to 4 years of clinical follow-up of ~68,000 outpatients from approximately 5,000 sites in 44 countries in men ≥ 45 years with either CAD, CVD, PAD, or who had at least 3 coronary risk factors present.

REGICOR (Registi: Fironi del COR). Population-based study designed to examine the prevalence of CVD risk factors, as well as the incidence and death rates associated with CHD, in the province of Gerona, Spain, in persons 25–74 years old. The reference population was composed of 189 towns and nearly 510,000 inhabitants. This study was carried out in 1995/1996.

Register of Information and Knowledge about Swedish Heart Intensive Care Admissions (Riks-HIA) (updated and renamed to SWEDE-HEART). This investigation collects information on patients admitted to the ICUs of participating hospitals with AMI throughout Sweden. The registry started in 1995, with 19 participating hospitals, and has increased gradually over time to include 70 of 78 hospitals throughout Sweden. This registry has been recently updated and renamed to include patients admitted with an ACS to 71 of 74 hospitals throughout Sweden (SWEDE-HEART).

Sino-MONICA Project. This population-based study compared the CVD risk factor profile of persons from different race ethnicities residing in Ontario, Canada, over the period 1996–2007.

Statistics Canada National Health Survey. This was a 7-year study designed to monitor trends and determinants of CVD in geographically defined populations residing in different parts of China between 1987 and 1993. Adults between the ages of 35–64 years were targeted for this population-based surveillance system.

Survey of Acute Myocardial Infarction and Ischaema (SAMII) in the United Kingdom. The original sampling frame for this study was all 248 acute nonteaching U.K. hospitals serving a population of approximately 42 million people. A random sample of 118 hospitals was selected, and of these, 94 (80%) provided data on patients hospitalized with an ACS during the mid-1990s.

Thai Acute Coronary Syndrome Registry (TACSR). This registry included consecutive patients with an ACS enrolled from 17 medical centers in Bangkok and other regions in Thailand between 2002 and 2005. In this registry, 5,537 patients had a discharge diagnosis of an ACS.

World Health Organization STEPwise Approach to Surveillance of Noncommunicable Disease Risk Factors (STEPS). The STEP program is a standardized method for collecting, analyzing, and disseminating data on chronic disease risk factors and stroke in low and middle income countries. A secondary goal of the STEPS program is to help countries build and strengthen their capacity to conduct surveillance in men and women aged 25–64 years.

CHRONIC LUNG DISEASE

Asthma, Chronic Bronchitis, and Respiratory Symptoms Among Adult Estonians and Non-Estonians (FinEsS-study). In the mid-1990s, a postal questionnaire survey was carried out for purposes of assessing differences in the prevalence of asthma, chronic bronchitis, and symptoms of respiratory disease in various population groups residing in Estonia. Based on self-reported responses to a standardized questionnaire, the prevalence of physician-diagnosed asthma was approximately 2.0%, whereas the prevalence of physician-diagnosed chronic bronchitis was 10.5%.

Asthma and COPD in Southern Finland. The data for this study were derived from a random sample of 4,300 men and women aged 18–65 years who were living in Southern Finland in 1996. Based on the responses to several standardized questionnaires, the prevalence of asthma was 5.3% whereas the frequency of COPD was 3.6%.

BOLD (Burden of Obstructive Lung Disease). This international study was designed to assess the prevalence of chronic obstructive pulmonary disease (COPD) and its predisposing factors and determine whether variation in these endpoints existed between participating sites. Individuals residing in major cities (e.g., Manila, Philippines; Cape Town, South Africa) from 12 countries participated in this multinational prevalence study of COPD. Adult participants ≥ 40 years (n = 9,425) were selected by a random sampling design. These individuals underwent spirometry testing and completed various questionnaires about their respiratory symptoms, health status, and exposure to risk factors for COPD.

China COPD Prevalence Study. For purposes of providing insights into the prevalence of COPD in China, a population-based epidemiologic study of COPD was conducted in 7 provinces/cities throughout China over a 2-year period beginning during the fall of 2002. Trained interviewers used a standardized questionnaire from the BOLD Study to assess COPD and respiratory symptoms, and subjects underwent spirometry examination. More than 20,000 individuals completed spirometry testing.

Chronic Bronchitis Among French Adults. This study assessed the prevalence of symptoms suggestive of chronic bronchitis in a large sample of the French population that consisted of more than 14,000 persons aged ≥ 25 years. The prevalence of chronic bronchitis was 4.1% based on participants' responses to a mailed questionnaire.

Chronic Bronchitis in South African Adults. This was a large national household survey of adults living in South Africa in 1998 designed to determine the prevalence and predictors of chronic bronchitis. A working definition of chronic bronchitis was utilized and peak expiratory flow was assessed. In the 5,671 men studied, the prevalence of chronic bronchitis (2.3%) was slightly lower than the prevalence of chronic bronchitis in women (n = 8,155; 2.8%). In multivariable adjusted models, several sociodemographic and lifestyle factors were associated with chronic bronchitis.

Comparative Study of Respiratory Symptoms and Diseases Between Northern Sweden and Northern Finland: the FinEsS Study. This study examined the prevalence rates of respiratory symptoms, asthma, and chronic bronchitis in residents of Norrbotten providence, Sweden and Lapland region, Finland, using standardized questions about respiratory symptoms and pulmonary diseases. Questionnaires were completed by 7,014 residents of Norrbotten and by 6,633 residents of Finnish Lapland. Physician-diagnosed chronic bronchitis was reported by approximately 4% of the Swedish population and by 3% of Finnish residents. The rates of other respiratory conditions (e.g., chronic cough, sputum production) were also reported.

COPD Among Canadians. Data from 7,210 individuals aged 35–64 years who participated in the National Population Health Survey of Canadians in 1994/1995 were utilized to assess the prevalence of chronic bronchitis/emphysema in Canadians. Based on an individual's response to a single question about whether COPD had ever been diagnosed by a health professional, the prevalence of COPD was approximately 2.4% in men and 3.8% in

women. Advanced age, history of allergies, low income, high BMI, and being either a current or ex-smoker were significantly associated with the presence of bronchitis/emphysema.

European Community Respiratory Health Study (ECRHS). This study examined the prevalence rates of asthma and allergic disease in young adults between the ages of 20–44 years in several European countries using a standardized protocol. This multicenter, multinational study began collecting baseline data in 1990, and a subsequent follow-up study, ECRHS II, was carried out between 1998 and 2002. A total of 56 centers from 25 countries took part in the baseline data collection activities of this study.

Guangzhou [China] Biobank Cohort Study. The Guangzhou Biobank Cohort Study includes older (≥ 50 years) adult residents of Guangzhou, China, who underwent measurement of their lung function under standardized conditions in the mid-2000s. A total of more than 8,000 healthy community-dwelling participants underwent spirometry testing, and the prevalence rates of prior TB and airflow obstruction in this cohort were assessed.

IBERPOC Study in Spain. This population-based study was carried out in 7 different geographic areas of Spain for purposes of assessing the prevalence of COPD and its risk factors. Fieldwork was performed in 1996/1997, and personal interviews and spirometry were carried out in approximately 4,000 men and women aged 40–69 years. The prevalence rates of COPD were considerably higher in men (14%) than in women (4%). Geographic variation in the prevalence rates of COPD was also reported among the 7 population settings.

Meta Analysis of COPD Prevalence Surveys. This publication was a meta-analysis of surveys examining the prevalence of COPD in persons ≥ 40 years. The authors identified 101 overall prevalence estimates of COPD from 28 different countries. Estimates were provided of COPD, of chronic bronchitis alone, and of emphysema alone.

MIDSPAN Studies. The MIDSPAN studies consisted of a number of occupational and general health studies that began in the 1960s and included nearly 30,000 people from Scotland and the United Kingdom. These studies were based in factories and other workplaces in Scotland, in a general population residing in a Hebridean island (Tiree), and two additional studies were carried out in residents of the towns of Paisley and Renfrew. Lung function testing and cardiorespiratory health status was performed in each of the MIDSPAN study sites.

PLATINO (Latin American Project for the Investigation of Obstructive Lung Disease). This study, which was carried out in population samples in residents of five major cities in Latin America (Sao Paulo, Brazil; Santiago, Chile; Mexico City, Mexico; Montevideo, Uruguay; and Caracas, Venezuela), examined the prevalence rates of COPD and associated mortality. This study began in 2002 and employed a 2-stage sampling strategy for identifying population samples of adults ≥ 40 years old. These individuals completed several study questionnaires and underwent spirometry testing. Approximately 5,500 men and women participated in this cross-sectional prevalence study.

Prevalence and Correlates of Airway Obstruction in South Korean Adults. A cross-sectional population-based study of residents of Ansan City, near Seoul, South Korea, was carried out in men and women ≥ 18 years. Interviews and physical examinations were carried out with study participants, including pulmonary function tests. The prevalence rates of airway obstruction were reported for men (17.0%) and for women (5.6%).

Prevalence and Risk Factors for Chronic Bronchitis in Pelotas, Brazil. A population-based cross-sectional survey was carried out among adult residents of an urban area (Pelotas) of southern Brazil during the winter of 1990. A total of 1,053 individuals aged ≥ 40 years participated in this survey and 12.7% were classified as having chronic bronchitis based on findings from a standardized questionnaire. Low family income and level of education, current cigarette smoking, and a history of major respiratory illnesses were associated with chronic bronchitis.

Prevalence and Treatment of Chronic Airways Obstruction in U.K. Adults. A mailed questionnaire was sent to middle-aged (≥ 45 years) white men and women residing in central Manchester, UK, in the early 1990s. In the

surveyed inner-city population (n = 723), the prevalence of asthma/bronchitis was assessed whereas chronic airways obstruction was assessed by pulmonary function tests in a sample of respondents.

Prevalence of Respiratory Symptoms in Northern and Central Italy (Po Delta and Pisa Study). Four cross-sectional general population surveys were carried out in residents of Northern and Central Italy between the late 1980s and early 1990s for purposes of assessing the frequency of respiratory symptoms and pulmonary disease in populations living in an urban and in a rural area that were characterized by different levels of outdoor air pollution.

Respiratory Symptoms in Elderly Chinese Living in Hong Kong. In the early 1990s, an age stratified sample of elderly (≥ 70 years) Chinese men and women was studied (n = 2,032). Standardized questionnaires about participants' lung health were completed, and the prevalence of various respiratory symptoms as well as several pulmonary diseases was assessed.

Swiss Study of Air Pollution and Lung Diseases in Adults (SAPALDIA). This is a multicenter cohort study that has examined the association between exposure to air pollutants and respiratory symptoms in adults residing in 8 areas throughout Switzerland. This study was initiated in 1991, and nearly 10,000 subjects completed a standardized baseline questionnaire on respiratory health and attended a health examination.

Trends in COPD in U.K. Women and Men. Data from the Group Practice Research Database (GPRD) were used for purposes of examining trends in the prevalence of COPD in British residents between 1990 and 1997. The GPRD is a large computerized database that included data from more than 3 million patients who had been seen in more than 500 primary care practices. Over the period under study, the annual prevalence rates of COPD increased in women (0.8% 1990; 1.4% 1997) as well as in men (1.3% 1990; 1.6% 1997).

Appendix C

Committee Biosketches

Elizabeth Barrett-Connor, M.D. (*Chair*), is Chief of the Division of Epidemiology and Distinguished Professor in the Departments of Family and Preventive Medicine and Medicine at the University of California, San Diego School of Medicine, in La Jolla.

Dr. Barrett-Connor earned a medical degree from Cornell University Medical College, in New York, New York. She completed an internal medicine internship and a residency at the University of Texas Southwestern Medical School, in Dallas, followed by postgraduate training in infectious diseases at the University of Miami School of Medicine, in Florida. Her research concerns healthy aging with a particular focus on gender differences and women's health. She is author of more than 800 publications.

Dr. Barrett-Connor is founder and director of the Rancho Bernardo Heart and Chronic Disease Study, begun in 1972, with continuous support from the National Institutes of Health (NIH). She has served as principal investigator of several multicenter clinical trials, including the Postmenopausal Estrogen/Progestin Interventions trial, the Heart and Estrogen-Progestin Replacement Study, the Raloxifene Use in the Heart Study, and the Diabetes Prevention Program.

Dr. Barrett-Connor is past president of the Epidemiology Section of the American Public Health Association, the Epidemiology Council of the American Heart Association, the Society for Epidemiologic Research, and the American Epidemiological Society. She has been a member of the Armed Forces Epidemiology Board, the Advisory Council of the National Institute on Aging, the Board of the Menopause Society, and the Advisory Committee of the Millennium Cohort Study. She is a Master of the American College of Physicians of Medicine and a member of the Institute of Medicine. Her many honors include the National Osteoporosis Foundation 2009 Living Legacy Award and four NIH MERIT awards.

John Z. Ayanian, M.D., M.P.P., is professor of medicine and health care policy at Harvard Medical School and professor of health policy and management at the Harvard School of Public Health. He is the director of the Harvard Fellowship in General Medicine and Primary Care, director of the Health Disparities Research Program of the Harvard Catalyst, and leader of the Outcomes Research Program of the Dana-Farber/Harvard Cancer Center. He is also a practicing general internist at Brigham and Women's Hospital.

Dr. Ayanian's research focuses on the effect of patients' race, ethnicity, gender, insurance coverage, and socioeconomic characteristics on access to care and health outcomes, and the impact of physicians' specialty and organizational characteristics on the quality of care. His recent studies have assessed racial disparities in quality

of care in Medicare health plans, the health effects of Medicare coverage for previously uninsured adults, and the quality of cancer care by race, ethnicity, and language.

Dr. Ayanian received his B.A. degree summa cum laude with distinction in history and political science from Duke University, M.D. degree from Harvard Medical School, and M.P.P. degree in health policy from the Harvard Kennedy School of Government. He has served on Institute of Medicine (IOM) committees on the Consequences of Uninsurance (2000–2004), Guidance in Designing a National Health Care Disparities Report (2001–2002), Cancer Survivorship (2004–2005), Health Insurance Status and Its Consequences (2008–2009), and Standardized Collection of Race/Ethnicity Data for Healthcare Quality Improvement (2009). Dr. Ayanian is a fellow of the American College of Physicians and an elected member of the American Society for Clinical Investigation and the Association of American Physicians.

E. Richard Brown, Ph.D., is the director of the UCLA Center for Health Policy Research; he is also a professor in the Department of Health Services and the Department of Community Health Sciences in the UCLA School of Public Health. Brown founded the Center in 1994. It has since become one of the nation's leading health policy research centers and the premier source of health policy information and analysis on California's population. The Center conducts research on a wide range of health issues and provides extensive public service to policy makers, advocates, and the media.

Brown's research and publications focus on health insurance coverage, the lack of coverage and the effects on access of public policies and economic and market conditions. His work and other studies by the Center's researchers have been used by California's governors, legislative leaders, and advocates in crafting health care legislation, policies, and programs.

Brown is the principal investigator for the California Health Interview Survey (CHIS), the nation's largest state health survey. CHIS provides statewide and local-level estimates for California's diverse population and covers a broad range of health topics, including health status and conditions, health disparities, health insurance, and access to health care.

Brown also has been extensively involved in the analysis and development of public policies, with particular emphasis on national health care reform. He has served as a senior health policy adviser to the Barack Obama for President Campaign, as health policy adviser to three members of the U.S. Senate and as a full-time senior consultant to President Clinton's Task Force on National Health Care Reform. Brown is a past president of the American Public Health Association. He received his Ph.D. in sociology of education from the University of California, Berkeley.

David B. Coultas, M.D., is currently Vice President for Clinical Affairs and Professor and Chairman of the Department of Medicine at the University of Texas Health Science Center at Tyler. He completed training in internal medicine and pulmonary disease at the University of New Mexico, and was a member of the University of New Mexico faculty for 16 years and Chief of the Division of Epidemiology and Preventive Medicine for 6 years. Subsequently, he was Associate Chairman of Internal Medicine at the University of Florida HSC/Jacksonville. His personal research interests include the epidemiology of pulmonary diseases and health outcomes research, and his projects have focused on patients with interstitial lung diseases, environmental and occupational lung diseases, and chronic obstructive pulmonary disease.

Charles K. Francis, M.D., MACP, FACC, is professor of medicine, Robert Wood Johnson Medical School (UMDNJ) and director of cardiovascular research at the Jersey Shore University Medical Center. Dr. Francis is the former director of the Center on Health Disparities and Rudin Scholar in Urban Health of the New York Academy of Medicine. In addition to his interest in racial and ethnic health disparities, medical education, and health services research, he has contributed to the literature in the areas of coronary artery disease, congestive heart failure, thrombolysis in myocardial infarction, hypertensive heart disease, mitral valve insufficiency, health and public policy, and health care for minorities. Dr. Francis has served as president of the American College of Physicians, president of the Charles R. Drew University in Los Angeles, president of the American Heart Association Western

States Affiliate, Los Angeles County Division, and the American Heart Association, Connecticut Affiliate and as chair of the Council on Clinical Cardiology of the American Heart Association. He has also served on the National Board of Directors of the American Heart Association, the Board of Directors of the American Board of Internal Medicine (ABIM), the Board of Directors of the New York Academy of Medicine, as past chair of the Board of the Association of Black Cardiologists, and on the Board of Governors of the Clinical Center at NIH. Dr. Francis is board certified in Internal Medicine and Cardiovascular Disease and is a Fellow of the American College of Cardiology and Master of the American College of Physicians. He is the recipient of the Louis B. Russell Memorial Award presented by the American Heart Association, the Daniel D. Savage, M.D. Memorial Award presented by the Association of Black Cardiologists, the Distinguished Alumni Faculty Award, Cardiology Division, Yale University School of Medicine and the Jefferson Alumni Achievement Award, Jefferson Medical College. He is an IOM member. Dr. Francis received his undergraduate degree from Dartmouth College and his medical degree from the Jefferson Medical College in Philadelphia.

Robert J. Goldberg, Ph.D., professor of medicine and epidemiology at the University of Massachusetts Medical School, received a Ph.D. in epidemiology from the Johns Hopkins University School of Hygiene and Public Health. He is internationally recognized for his work in cardiovascular epidemiologic research, having served as principal investigator on multiple projects funded by NIH. Dr. Goldberg initiated the Worcester Heart Attack Study, ongoing since the late 1970s, to examine the incidence, survival rates, and management of acute myocardial infarction in residents of the Worcester metropolitan area. Findings from this landmark study, which is viewed as one of the premier epidemiologic studies of heart disease in the United States, have been published in the *New England Journal of Medicine* and the *Journal of the American Medical Association*. He is also leading a project titled "Community Trends in Heart Failure" that has been initiated with funding from the National Heart, Lung, and Blood Institute. Dr. Goldberg is actively involved in teaching public health and preventive medicine to medical students, residents, and community-based physicians. Recently, Dr. Goldberg became director of the Division of Epidemiology in a newly formed Department of Quantitative Health Sciences at the University of Massachusetts Medical School.

Lawrence O. Gostin, J.D., L.L.D., is professor of law; co-director, Georgetown/Johns Hopkins Joint Degree in Public Health and Law. He is also an adjunct professor at the Johns Hopkins School of Hygiene and Public Health, and a Fellow of the Kennedy Institute of Ethics. Professor Gostin was consulting legislative counsel to the U.S. Senate Labor and Human Resources Committee chaired by Senator Edward Kennedy. Professor Gostin is on the editorial boards of several journals, including law editor of the *Journal of the American Medical Association*. He is also on the advisory committees of the World Health Organization and the U.S. Centers for Disease Control and Prevention. Professor Gostin was also a member of the President's Task Force on National Health Care Reform.

Thomas E. Kottke, M.D., is an internationally recognized expert in the delivery of preventive services and the prevention of chronic diseases. While on the faculty of the Mayo Clinic School of Medicine, he developed the Southeastern Minnesota Womens' Health Project (R25CA57825) to improve breast and cervical cancer screening for women in Southeastern Minnesota and the Native WEB (CCU510175) to increase access to breast and cervical cancer screening for Native American women. Dr. Kottke has also designed and implemented trials to increase the delivery of smoking cessation services in medical practice (Doctors Helping Smokers; R01CA38361) and increase the delivery of preventive services in primary care (R01HS08091). Dr. Kottke designed and implemented a comprehensive heart disease prevention and treatment program in Olmsted County, Minnesota, CardioVision2020. Dr. Kottke has published more than 240 peer-reviewed papers, editorials, and book chapters, many on the development of systems in clinical practice to assure the delivery of preventive and chronic disease services. Dr. Kottke was a member of the first U.S. Preventive Services Task Force (USPSTF) and both AHCPR/AHRQ task forces for the development of smoking cessation intervention guidelines. Dr. Kottke has served as a consultant to the World Health Organization on the prevention and management of chronic diseases and is a member of the faculty of the World Health Organization Non-communicable disease prevention course.

Elisa T. Lee, Ph.D., is George Lynn Cross Research Professor of Biostatistics and Epidemiology and director of the Center for American Indian Health Research in the College of Public Health, University of Oklahoma Health Sciences Center. Dr. Lee's interests include the epidemiology of cardiovascular disease, diabetes, and eye disease, especially among American Indian populations (specifically the Strong Heart Study and the Oklahoma Native American EXPORT Center).

Current major research projects:

- Cardiovascular Disease in American Indians (Strong Heart Study—strongheart.ouhsc.edu)—A multicenter longitudinal study (since 1988) of heart disease and its risk factors in 13 American Indian tribes and communities, funded by the National Heart, Lung and Blood Institute (NHLBI) of NIH. Role: P.I. of the Oklahoma Center and Coordinating Center.
- Stop Atherosclerosis in Native Diabetics Study (SANDS)—A multicenter clinical trial to prevent heart disease by lowering blood pressure and LDL-cholesterol in American Indians who have diabetes, funded by NHLBI/NIH. Role: P.I. of Oklahoma Center.
- Native Healthy Lifestyle: A Return to Balance (Balance Study)—A culturally appropriate intervention clinical trial to prevent heart disease in high-risk American Indians, funded by NHLBI/NIH. Role: P.I.

David M. Mannino, M.D., is currently professor of medicine in the Department of Preventive Medicine and Environmental Health and the Division of Pulmonary, Critical Care, and Sleep Medicine at the University of Kentucky in Lexington, Kentucky, and the director of the Pulmonary Epidemiology Research Laboratory. He was formerly the chief science officer of the Centers for Disease Control and Prevention's Air Pollution and Respiratory Health Branch. While at CDC he was the lead author on key publications reporting on the epidemiology of chronic obstructive pulmonary disease (COPD) and asthma. He has more than 160 publications in leading peer-reviewed journals on topics that range from the epidemiology of lung disease to health effects related to air pollutant exposure. He is an active member of and adviser to several professional organizations, including the COPD Foundation, the USCOPD Coalition, and the Alpha-1 Foundation. He is an associate editor of the journals *Thorax*, *International Journal of Tuberculosis and Lung Disease*, and the *Clinical Respiratory Journal*.

K. M. Venkat Narayan, M.D., M.Sc., M.B.A., is the Ruth and O.C. Hubert Professor of Global Health & Epidemiology at Rollins School of Public Health, Emory University in Atlanta, Georgia. Dr. Narayan is a product of three continents and has a richly diverse background. He is a physician-scientist trained in internal medicine, geriatric medicine, and preventive medicine, and specializes in the epidemiology and prevention of diabetes, obesity, and vascular diseases.

Until 2006, he led the Diabetes Epidemiology and Statistics Branch at the Centers for Disease Control and Prevention (CDC). Dr. Narayan was a Visiting Scientist at NIH for 4 years before joining CDC in 1996. He is an investigator in several large, multi-center, national studies of diabetes (e.g., The TRIAD Study of diabetes quality of care, Diabetes Prevention Program [DPP], The ACCORD Trial of CVD Prevention, and The SEARCH study of diabetes in children).

He has authored/coauthored more than 200 peer-reviewed publications, including invited textbook chapters and several editorials. Dr. Narayan co-directs the Emory-MDRF Global Diabetes Research Center and an Ovations/NHLBI Global Center of Excellence for Cardiometabolic Diseases. He is a fellow of the American College of Physicians, Royal College of Physicians of Ireland, American Heart Association, and the Faculty of Public Health Medicine of the Royal College of Physicians (UK).

Sharon-Lise T. Normand, Ph.D., M.Sc., is professor of health care policy (biostatistics) in the Department of Health Care Policy at Harvard Medical School and professor in the Department of Biostatistics at the Harvard School of Public Health. Her research focuses on the development of statistical methods for health services and outcomes research, primarily using Bayesian approaches to problem solving, including methods for causal inference, provider profiling, item response theory analyses, meta-analyses, latent variable analysis, and evaluation of medical devices in randomized and non-randomized settings. She serves on several task forces for the American Heart Association and the American College of Cardiology, and was a member of the FDA Circulatory System

Devices Advisory Panel, and the Massachusetts Cardiac Care Quality Advisory Commission. She is currently a member of the IOM's Committee of Aerospace Medicine and the Medicine of Extreme Environments and its Committee on Future Directions for the National Healthcare Quality and Disparities Reports. Dr. Normand is director of Mass-DAC, a data coordinating center that monitors the quality of cardiac surgeries and coronary interventions in all Massachusetts' acute care non-federal hospitals. She earned her Ph.D. in biostatistics from the University of Toronto, and holds an M.S. as well as a B.S. in statistics. Dr. Normand is a fellow of the American Statistical Association, of the American College of Cardiology, of the American Heart Association, and is an Associate in the Society of Thoracic Surgeons.

David J. Pinsky, M.D., is the division chief of Cardiovascular Medicine at the University of Michigan (U-M), as well as a director of the U-M Cardiovascular Center. Prior to joining U-M in March 2003, Pinsky was director of research for the Cardiovascular Disease Training Program at Columbia Presbyterian Medical Center in New York and associate professor of medicine at Columbia University College of Physicians & Surgeons. He served at Columbia University from 1992–2003. He earned his medical degree from Ohio State University and performed his medicine residency, as well as his research fellowship in heart failure at Mount Sinai Hospital in New York. He also performed research fellowships in cardiology and vascular biology at Columbia. He has participated in strategic reviews and led a number of review panels at NIH. As a result of his groundbreaking research, Dr. Pinsky has earned a reputation as one of the country's foremost experts in understanding the relationship between blood flow and heart and brain diseases. His research efforts have earned him numerous grants and awards, including the American Heart Association Melvin Marcus Young Investigator Award in cardiovascular physiology and the American Heart Association Established Investigator Award.

Lorna Thorpe, Ph.D., M.P.H., joined as director of the Epidemiology and Biostatistics Program at the new City University of New York (CUNY) School of Public Health in November 2009. Prior to that, she served for 5 years as Deputy Commissioner for the New York City (NYC) Health Department, directing the Division of Epidemiology. At the NYC Health Department, Dr. Thorpe played a central role in cementing the Health Department's reputation for expertise and innovation in using data to understand problems and evaluate solutions, while increasing the agency's collaborations and visibility with outside organizations such as academic institutions, sister city agencies, community-based organizations, and federal partners. Specifically, Dr. Thorpe oversaw many innovative scientific initiatives aimed at understanding the health of NYC residents, including the launch of several large population-based health surveys, expansion of injury surveillance, improving NYC birth and death registration, and guiding the tracking of more than 71,000 exposed individuals participating in the World Trade Center Health Registry. She also played a leading role in expanding public health training opportunities for Health Department staff and future public health professionals.

Dr. Thorpe previously served as a CDC chronic disease epidemiologist and she began her CDC career as an Epidemic Intelligence Service (EIS) Officer in international tuberculosis (TB) control. Dr. Thorpe completed her Ph.D. in epidemiology at the University of Illinois at Chicago, M.P.H. at the University of Michigan, and B.A. at Johns Hopkins University. She has lived and worked internationally and has published widely on both chronic and infectious disease topics.

William M. Tierney, M.D., is the executive director of the Regenstrief Center for Healthcare Improvement and Research (RCHIR) and senior research scientist, Regenstrief Institute, Inc.; Chancellor's Professor in the Department of Medicine of the Indiana University School of Medicine; director of research for the Indiana University Kenya Program; director of global health for the Indiana Clinical and Translational Sciences Institute, and director of ResNet, one of the oldest and most productive practice-based research networks in the United States.

Dr. Tierney is an internationally recognized expert in medical informatics and health services research, known for implementing and assessing electronic medical record systems to enhance quality of care. He led the team that was first to demonstrate that computerization of hospital orders can substantially reduce cost and medical errors. The technology he evaluated now supports care for large patient populations in Indiana and sub-Saharan Africa. In addition to informatics-based health services research, he has also performed dozens of epidemiologic studies

utilizing the clinical data stored in the clinical data repositories created by the Regenstrief Institute and Indiana University's collaborative care program in east Africa.

Paul J. Wallace, M.D., is the medical director of Health and Productivity Management Programs at the Permanente Federation and senior adviser to Avivia Health from Kaiser Permanente. He is a graduate of the University of Iowa School of Medicine and completed further training in Internal Medicine and Hematology at Strong Memorial Hospital and the University of Rochester. Dr. Wallace is a member of the IOM Board on Population Health and Public Health Practice and served on the IOM Planning Committee for a Workshop on a Foundation for Evidence-Driven Practice: A Rapid-Learning System for Cancer Care, the IOM Planning Committee for a Workshop on Applying What We Know: Best Practices in Evidence-Based Medicine, and the IOM Subcommittee on Performance Measures. Dr. Wallace is an active participant, program leader, and perpetual student in clinical quality improvement, especially in the area of translation of evidence into care delivery using people and technology-based innovation supported by performance measurement. As Kaiser Permanente's (KP's) Medical Director for Health and Productivity Management Programs, he leads work to extend KP's experience with population-based care to further develop and integrate wellness, health maintenance, and productivity enhancement interventions. He is also active in the design and promotion of systematic approaches to comparative effectiveness assessment and accelerated organizational learning. He was previously the executive director of KP's Care Management Institute (CMI) from 2000–2005 and continues as a senior adviser to CMI and to Avivia Health, the KP disease management company established in 2005. Board certified in Internal Medicine and Hematology, he previously taught clinical and basic sciences and investigated bone marrow function as a faculty member at the Oregon Health Sciences University. Dr. Wallace is a member of the Board for AcademyHealth, and serves as the Board Chair for the Center for Information Therapy. He has previously served on the National Advisory Council for AHRQ, the Medical Coverage Advisory Committee for the Center for Medicare & Medicaid Services, the Medical Advisory Panel for the Blue Cross and Blue Shield Technology Evaluation Center, the Board of Directors for DMAA: The Care Continuum Alliance, and the Committee on Performance Measurement and Standards Committee for NCQA.